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- General practitioners from the greater metropolitan area of Melbourne
- Pharmacists from the Pharmacy Guild (Victoria)
- RDNS Community Nurses
- Older people
- People with dementia
- Family carers
# Project Team

<table>
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<tr>
<th>Name</th>
<th>Position</th>
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</tbody>
</table>
Table of Contents

Executive Summary ............................................................................................................. 1
1. Introduction ................................................................................................................... 3
   Background ..................................................................................................................... 3
2. The Journey ................................................................................................................... 9
3. Self Management........................................................................................................... 11
   Motivation and Incentives............................................................................................. 11
   Values and Beliefs About Medicines ............................................................................ 15
   Relationship with Health Professionals ........................................................................ 19
   Adapting to Compromised Ability ................................................................................ 22
   Summary ....................................................................................................................... 29
4. Something Changes ..................................................................................................... 31
   Changing Ability ........................................................................................................... 31
   Environmental Factors ................................................................................................. 34
   Encouraging Self Management ..................................................................................... 37
   Decision to Seek More Help ......................................................................................... 38
   Who Provides the Assistance ......................................................................................... 38
   Summary ....................................................................................................................... 39
5. Family Member Advocacy and Carer Role .............................................................. 41
   Advocacy ...................................................................................................................... 41
   Expectations .................................................................................................................. 43
   Impact of the Caring Role ............................................................................................. 45
   Carer Ability to Carry out the Role ............................................................................... 46
   Carer Medicine Management Strategies ....................................................................... 46
   Factors That Support the Carer Role ............................................................................. 51
   Summary ....................................................................................................................... 52
6. Locus of Control and the Medication Team ............................................................. 53
   Control .......................................................................................................................... 53
   Working as a Medication Team .................................................................................... 54
   Assessment .................................................................................................................... 55
   Barriers to Team Work ................................................................................................. 58
   Developing Collaborative Relationships ...................................................................... 60
   Summary ....................................................................................................................... 63
7. Discussion ..................................................................................................................... 65
   Person-Centred Medicines Management and the Active Service Model...................... 65
   Identification of Strengths and Weaknesses and Personal Resources for Medicine Management .................................................................................................................. 69
8. References .................................................................................................................... 75
   Appendix 1 .................................................................................................................... 79
   Appendix 2 .................................................................................................................... 85
   Appendix 3 .................................................................................................................... 86
   Appendix 4 .................................................................................................................... 88
   Appendix 5 .................................................................................................................... 90
   Appendix 6 .................................................................................................................... 91
Executive Summary

This report describes the thoughts and perceptions of older people, people with dementia, family carers and health professionals regarding management of medicines in the community. The findings have been used to develop a tool to assess the person’s capacity to self-manage their medicines.

Using a qualitative method, the research underpinning the project was grounded theory using semi-structured interviews and focus groups. Data collection was guided by two goals: understanding the needs of people in maintaining independence with medicine management, and identifying the views of family members, community nurses, (General Practitioners (GPs) and pharmacists about how current medicine management practices could be improved.

The key finding was that medicine management was a journey and had four distinct stages:

Self management described how motivations and incentives, the person’s values and beliefs, their relationship with their health professional and the strategies they used to adapt to age related changes supported their independence with medicine management.

Something changes identified factors that contributed to the transition from self management to needing more help. These included functional and cognitive decline and disruption to medicine routines. The increased potential for adverse drug events precipitated the family member to move into the carer role, or the community nurse replicated this role when the person lived alone and had no carer.

Family member advocacy and the carer role identified the impact of the caring role as under-recognised by health professionals. Family carers utilise a range of strategies to enable them to undertake medicines management for another person.

Locus of control and the medication team described current assessment practices, barriers to team work, and changes needed to enable development of collaborative relationships.

The outcomes of this study indicate that:

- A person-centred and strengths-based approach to assessment should be undertaken.
- More consideration should be given to the family carer’s role.
- Interpreters and translated medicines information should be made available when working with non-English speaking people.
- The person’s motivations and incentives to take medicines and their attitudes towards their information needs should be explored.
- Strategies to sustain prescription management should be offered to older people.
- Medicine management requires ongoing monitoring.

Future research is required to test the tool for validity and reliability in the clinical setting.
1. Introduction

Background

Community nurses assume a wide range of roles in relation to medicine management, with the key responsibility being assessment of the client’s ability to self medicate. The Australian Pharmaceutical Advisory Council (Australian Pharmaceutical Advisory Council, 2006) identified that “consumers should be encouraged to maintain their independence for as long as possible, including managing their medicine in a safe and effective way.” Where clients have been identified as experiencing problems in this task, the likely outcome for the client is that their medicines will be administered by the community nurse. However, it is unclear what parameters are used by individual nurses when assessing medicine self management abilities and planning care for their clients.

Approaches to care for older people and those with dementia in the community are currently undergoing a shift in focus. Nationally, the community healthcare sector is implementing models of care that are person-centred, goal-oriented and enabling; working with clients to achieve greater independence and wellbeing. In Victoria, this approach is known as the Active Service Model. (State Government of Victoria, 2008) This project has been developed to inform nursing practices that support safe and independent medicine management by older people and people with dementia living in the community.

What is medicines management?

Successful medicine management is a multifaceted task requiring a person to possess both cognitive and physical abilities. For the purposes of this project, the working definition of medicine management that has evolved from the literature is as follows:

Medicine management should involve safe and rational prescribing practices, communication and understanding of the persons’ medicine taking beliefs and behaviours, understanding of their ability to obtain and self administer the medicine, ensure the person has sufficient knowledge of their medicine regime and to ensure that interventions are implemented before the risk of harm from adverse medicine events or error can occur.

The consequences of poor medicine management include suboptimal symptom management or disease progression, an increase in the need for diagnostic investigations, an escalation of medicines being prescribed that lead to increased risks of adverse drug events, and hospital admission and readmission (Arlt, Lindner, Rosler, & von Renteln-Kruse, 2008). These, in turn, have cost implications which were last estimated in Australia in 2002 to be in excess of $350 million (Australian Council for Safety and Quality in Healthcare, 2002).

Ageing, medicine, and risk

Research indicates that poor management of medicines occurs across the age span (Arlt et al., 2008), however, the older adult is more likely to experience difficulties by the very nature that they are more susceptible to intercurrent health problems, be prescribed more medicines and be at risk of adverse drug events (Arlt et al., 2008; Marek & Antle, 2006).

The inability to take medicines as prescribed occurs in 40–45% of older adults (MacLaughlin et al., 2005). There are numerous risk factors associated with ageing such as sensory deficit, impairment of dexterity and coordination, cognitive impairment, and dementia, as well as conditions such as incontinence, dizziness, and falls, which occur.

1 Terminology relating to ‘medicine’ and ‘medication’ in this report will reflect those used in the Australian Pharmaceutical Advisory Council (2006): Guiding principles for medication management in the community.
either singularly, or more particularly, in combination that will influence self management of medicine (Arlt et al., 2008).

Unfortunately there is a double jeopardy associated with the presence of chronic illness and ageing. Not only do chronic conditions such as diabetes, heart failure and chronic obstructive airways disease have a negative impact on cognitive function, so do some of the drugs prescribed to treat these conditions. In turn the decreased cognitive functioning impairs the person’s ability to self medicate (Insel, Morrow, Brewer, & Figueredo, 2006).

There is conjecture in the literature about what determines the person’s ability to safely self manage their medicine. It is proposed that psychomotor and cognitive ability are the two key determinants that will affect the persons ability to maintain safety (Maddigan, Farris, Keating, Wiens, & Johnson, 2003). The cognitive capacity more specifically required for medicine management is the executive function that supports planning, organisation, initiation, perseveration, and regulation of a task to its completion. Psychomotor ability includes mobility and functional capacity, both of which can affect the person’s access to medicine, and involves the ability to open packaging, administer medicine, use devices such as inhalers and eye droppers, and apply topical preparations correctly (Thwaites, 1999).

The community dwelling older population face a number of challenges in managing medicines. In a 2002 Australian based study, only 10.8% of participants were able to undertake all medicine management tasks successfully. Challenges identified by participants included: difficulty reading a dot point matrix label on a box or bottle (25.2%), difficulty hearing medicine related instructions (3.6%), and difficulty using a Dosette (11.7%) or blister pack (13.5%). There were also problems for participants in differentiating between green, lavender and blue colour tablets (28.8%) and swallowing medicine (31.5%) (Johnson, Griffiths, Piper, Langdon, & Stephens, 2002, pp. 54–55). Problems related to swallowing medicines are more likely to be encountered in people with cerebrovascular, motor-neurone or Parkinson’s disease (Thwaites, 1999).

Physical problems may also encompass inability to open medicine containers or lids (Vik, Maxwell, & Hogan, 2003, as cited in University of Queensland, 2004). Eye drop administration has been found to be problematic for people who have hand tremors or difficulty moving their head, raising their arms or squeezing the bottle (Winfield, Jessiman, Williams, & Esakowitz, 1990). The ability to use inhalers may also be difficult for up to 60% of people, particularly those with hemiplegia, rheumatoid arthritis and cognitive impairment (Teale, Jones, Patterson, Kearney, Stanners, & Muers, 1995).

**Cognitive impairment, dementia, and medicine**

The person with dementia is more likely to be prescribed multiple medicines than their counterpart without dementia, although there are prescribing differences according to dementia subtype and stage of dementia (Arlt et al., 2008). Impairment of memory and cognition and forgetfulness contribute to poor medicine adherence in 16–40% of older adults (Arlt et al., 2008). The most common reason for failing to take medicine in this cohort is poor memory (Marek & Antle, 2006). Clients who experience difficulties in naming drugs and their dose instructions who also have a Mini Mental State Exam (MMSE) score of 24 and under are more likely to have difficulty in maintaining adherence to their medicines (Arlt et al., 2008).
The role of community health professionals in medicine management

Medicine management has always been an integral part of Royal District Nursing Service (RDNS) services, but today the amount of resources expended in this area is increasing. Almost 58% of all visits to RDNS clients now involve some form of support for medicine management; this equates to over one million visits a year. Driving this demand is the increasing number of older people now in RDNS care (almost 75% of clients are aged over 60 years) and data suggesting that 86% of this cohort use at least one prescription medicine (Australian Institute of Health and Welfare, 2002).

The major issues from the perspective of providers of home nursing care to members of these client groups are the inconsistencies in the assessment of client’s capacity to self administer their medicines. Anecdotal evidence in this area suggests that assessment of a person’s ability to self-administer medicines has focussed on deficits and on what healthcare providers think that person requires. Medicine management interventions based on these assumptions have not been effective in improving client health outcomes. There is a need for a shift in focus to a strength based and person centred approach.

Aim

This study aimed to explore the thoughts and perceptions of older people, people with dementia, family carers and health professionals regarding management of medicine in the community. The findings have been used to inform the development a tool for community nurses to use in the assessment of clients in their capacity to self medicate (Appendix 1).

Method

Using a qualitative method, the research underpinning the project was grounded theory using semi-structured interviews and focus groups. Data collection was guided by two goals: understanding the needs of people in maintaining independence with medicine management, and identifying the views of family members, community nurses, GPs, and pharmacists about how current medicine management practices could be improved.

Ethics

Ethical approval for the study (project number 117) was provided by the Royal District Nursing Service Human Research Ethics Committee on 20th April 2010.

Inclusion criteria

The principal criteria for inclusion in the study were older people aged 65 years and over and people with cognitive impairment or early stage dementia who self administer prescribed and non-prescribed medicines who could describe their experiences related to the challenges in the self management of their medicine. Also, family members who have an awareness or input into supporting another to self administer their medicines, and health professionals (GPs, Pharmacists and community nurses) with direct involvement in medicine management with the target group or have an interest in the issue under discussion.
Recruitment

In order to maximise the range of views, participants were purposefully sought to provide variation on the topic. Participants were recruited to the study by invitation (Appendix 2) and recruitment was facilitated by different pathways. People with dementia and family carers\(^2\) of people with dementia were recruited with the assistance of Alzheimer’s Australia (Victoria) and RDNS, using a snowballing approach which involves asking participants to make referrals to other participants (Polit & Tatano Beck, 2008). Older people and family members of older people were recruited with the assistance of Carers Victoria and RDNS also through the snowballing technique. Recruitment of health professionals was supported by Divisions of General Practice, Pharmacy Guild (Victoria) and RDNS.

Plain language statements (Appendix 3) were used to describe the project and seek consent. Standard consent procedures were used for all participants, however, for people with dementia, the person’s capacity to provide consent was also determined prior to recruitment.

Participants

Recruitment to the project was carried out between May and December 2010, with a final recruitment rate of over 90%. Table 1 identifies the proposed sample size for people with dementia, older people and family carers and the numbers achieved. Table 2 identifies the proposed sample size for GPs, pharmacists and community nurses and the numbers achieved.

| Table 1: Older People, People with Dementia and Family Member Interviews |
|-------------------------------------------------------------|-----------------|------------------|
| Proposed sample size | Sample achieved |
| People with dementia | 10 | 8 |
| Family carers of people with dementia | 10 | 9 |
| Older people | 10 | 11 |
| Family carers of older people | 10 | 6 |

| Table 2: Health Professionals Focus Groups |
|---------------------------------------------|-----------------|------------------|
| Proposed sample size | Sample achieved |
| General Practitioners | 5 | 8 |
| Pharmacists | 5 | 4 |
| RDNS Community Nurses | 20 | 17 |

\(^2\) “A carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual: a) has a disability b) has a medical condition (including terminal or chronic illness); or c) has a mental illness; or d) is frail and aged”. (Carer Recognition Act 2010 (Cwlth), s.5, p.3)
Data collection

A series of focus groups of approximately one hour in duration were conducted with health professionals. Focus groups were chosen as they provide a resource effective way to congregate several health professionals and generate group interaction to collect data (Kitzinger, 1995). Focus groups were guided by use of use of semi structured questions (Appendix 6). Community nurses, general practitioners and pharmacists were asked how they identify when the person is at risk of medicine related problems; how they assess the risk of medicine errors and the person’s ability to take their medicines; how they take into consideration the person’s personal, cultural and health beliefs in medicine activities; and to explore the range of medicine interventions and support they offer to both the person and to family carers.

These health professionals were also asked to describe their roles within the medicine management continuum, how they work collaboratively with each other as well as the person and family carer and any suggestions they had on how this could be optimised.

Semi-structured interviews were conducted with older people, people with dementia and family carers. The interview was the chosen method for this group of participants because the researcher wanted to directly explore personal information, attitudes and beliefs (Beanland, Schneider, LoBiondo-Wood, & Haber, 1998) as well as providing the participant with the convenience of completing the interview in the venue of their choice, usually home. The interviews undertaken took an ‘assets based approach’ in that they aimed to identify and focus on the strengths of those interviewed. This approach allowed for a deeper understanding of this population and it allowed participants to “be part of the action, not as client or recipients of aid, but as full contributors to the community building process” (Kretzmann & McKnight, 1993, p. 6). Interviews were guided by the use of semi-structured questions (Appendices 4 and 5). Participants were asked about how they manage their medicines, drawing from their personal experiences related to any difficulties or challenges in self medicine management, and the support they receive from health professionals and family. We also asked them to advise us of the strategies and knowledge they use to promote their independence in managing their medicines.

Family members of older people and those living with dementia in the community were asked about their understanding of medicine management, the role they take in supporting another to self administer their medicine and any concerns this causes, how they identify that the person is experiencing difficulties and how they manage these difficulties and what support they receive from health professionals to undertake this role.

Analysis

Focus groups and interviews were audio recorded for accuracy and transcribed verbatim. All transcriptions were checked against the audio recording by the researcher to ensure accuracy and to de-identify data. The resultant data was managed through NVivo 8, a software program that facilitates the organisation of large amounts of data.

A constant comparative method of thematic data analysis (Lincoln & Guba, 1985) was used to explicate issues. Critical analysis was undertaken via team discussions.
Results

The combined data from the interviews and focus groups provided a rich and contextualised narrative of medicine management from multiple perspectives.

Quotes have been included in the results section to support the emergent themes. Words may have been added to ensure quotes make sense to the reader. Added words will be identified through use of square brackets [].

Throughout the report, participants have been referred to in the following way:

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>GP</td>
<td>General Practitioner/s</td>
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<tr>
<td>CN</td>
<td>Community Nurse/s</td>
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<tr>
<td>Pharm</td>
<td>Pharmacist/s</td>
</tr>
<tr>
<td>PWD</td>
<td>Person with Dementia</td>
</tr>
<tr>
<td>OP</td>
<td>Older Person</td>
</tr>
<tr>
<td>Carer PWD</td>
<td>Family Carer of Person with Dementia</td>
</tr>
<tr>
<td>Carer OP</td>
<td>Family Carer of Older Person</td>
</tr>
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This report will be presented as a journey with four distinct elements which will be discussed in more detail in the following chapters. Chapter 2 provides a brief overview of the journey of medicine management followed by chapter 3 where the self management experiences and strategies described by the older person and person with dementia are explored. Chapter 4 examines the changes that impact on the person’s ability to maintain independence and safe self administration of medicines, and chapter 5 describes the family carer role and experiences as they provide increasing assistance to their relative. Chapter 6 moves the focus to the way in which the medication team functions and issues for the health professionals. Following completion of chapters 3, 4, 5, and 6 the key considerations that will inform the development of the assessment tool will be explored. Chapter 7 will discuss the implications of these findings for person centred medicines management.
2. The Journey

The journey depicts the experiences of medicine management for participants (older people and people with dementia) in this study. It was an individualised and complex journey which, for some, started late in life. The key motivating factors on commencing and continuing a medication journey were the goals to establish safe self management and longevity. Underlying incentives that could negatively influence the person’s motivation to take medicines were fears of dependency, as well as fears of ageing and ill health. More positive influences were medicines that provided symptom relief and the GP prescribing behaviours and attitudes. Values and beliefs regarding medicines ranged from the belief that medicines were poison, to being necessary for life, and preferences for natural medicines. Participants were willing to compromise their values and beliefs if the motivation to take medicines was stronger. Other factors that promoted self management included the development and establishment of relationships with GPs and pharmacists. Valued characteristics included health professionals who engendered trust and confidence, were friendly and showed an interest in them as individuals. Giving and receiving information was an important component of self management, with many participants actively seeking information until they had established the level of understanding about their medicines they wanted. A range of age related changes that compromised the person’s ability to manage medicines were described, accompanied by the strategies they had developed to adapt to these to maintain their goal of self management and longevity.

Cognitive changes that affect short term memory were reported as the most difficult aspect of ability to manage medicines. There were a number of transient changes from external factors that would further reduce the person’s ability to self manage. These included multiple prescribers, admissions to hospital or respite and changes in the names and appearances of medicines. Family members became increasingly involved in supporting their relative to manage their medicines. The decision to seek more help with medicine management was multifaceted but most likely to be prompted by the participants no longer being able to maintain safety with self administration.

The family member assumed a carer role based on an advocacy approach and ongoing safe management of medicines. Health professionals were appreciative of their presence but failed to provide the education and support the family carer required to undertake this role. There were many factors that supported or hindered their ability to safely manage medicines for another person and family carers described how they had to develop systems, think ahead, and be more organised with some tasks such as prescription management. The continuity of the relationship with the health professionals was particularly important for family carers.

Once the older person or person with dementia was no longer able to adjust to their changing ability, the number of people involved in supporting medicine management increased. These people were described as the medication team. Understanding of each other’s roles and responsibilities within the medication team was important. Health professionals’ assessment practices were not based on validated tools and the Home Medicines Review (HMR), which does provide a systematic approach to assessment, was under utilised. Sharing of assessment findings was limited by barriers to team work which included working in silos, unsatisfactory communication processes and ineffective working relationships between professional groups. It was anticipated by the health professional participants that this situation could be transformed by improving the utilisation of the HMR, by using the GP practice as the central point to all professionals to improve relationships, and multidisciplinary working and the use of case conferencing to improve communication.
3. Self Management

Older people and people living with dementia in the community were interviewed about their personal experiences related to self medicine management and who they seek support from. The older participants were all living independently, with good social networks and did not have significant physical disability. The people with dementia were in the earlier stages of the disease and were in receipt of some level of assistance from a third party with their medicine. These participants had developed a range of strategies which they used to promote their independence in managing their medicines. Their independence was supported by a team approach of two or three people; that is, themselves, their GP and, for some, the pharmacist. This journey commences with the motivations and incentives of self medicine management and moves on to understand the values and beliefs that underpin medicine taking behaviours. The relationship that is developed with health professionals to support medicine self management is described along with the adaptations that older people make as they become increasingly affected by age associated functional changes.

Whilst the focus of this chapter is on the older person and person with dementia, quotes from health professionals have also been utilised to demonstrate when perceptions may correspond or differ and where this occurs they will be discussed. This chapter will discuss the following

- Motivation and incentives
- Values and beliefs about medicines
- Relationship with health professionals
- Adapting to changing ability.

**Motivation and Incentives**

The motivation and the incentive to carry out an act are closely related. Motivations are largely the reasons for a person to do something or behave in a certain way and the incentive is an act by another that will provide that motivation. In relation to the findings from this study it appeared that the motivation to take medicines as prescribed by the doctor tended to be based on the immediate experiences of the individual, these included their goal for self medicine management, fear of dependency and fears surrounding ageing and illness. The incentives to take medicines was informed by the therapeutic effect of the medicine with treatment of symptoms as the measure of benefit, the GP prescribing behaviours such as simplification of the medicine, use of negotiation skills, and their attitudes to ageing.

**Goals of self medicines management**

Half of the older person participants identified that the responsibilities associated with the self management of medicine largely comprised remembering to take the right tablets at the right time as prescribed by their doctor.

Well, you make certain that you’re really taking the right tablets and make certain that you take them at their prescribed time that’s prescribed by the doctor or chemist. (OP 1)

Remembering when to take them. That's number one I think and what to take at a particular time. (OP 2)

To take them on time, regularly, as directed by the chemist or doctor. (OP 11)

Older people described a number of strategies to achieve the goal; these included use of dose administration aids, recalling and checking instructions, counting the number of tablets to be taken or taking them in a set order.

Sometimes I write them down just to think — now I remember that and I usually do and if I don’t I ring them back and say what did you say? (OP 8)
I find myself counting them — when I’ve put them I think, oh, how many’s in there? Check how many’s in there. Make sure I’ve got them all. (OP 9)

Older people also viewed safety in relation to the potential for contra indications between medicines that they had purchased themselves or were issued by their GP and would check this with their pharmacist.

Or even ask the chemist when I go, what effect this would have and does it affect any other tablets? I’d always check on that. (OP 1)

Normally, if I go and ask for something, cough or colds or anything like that, and say what's the best thing for me? They usually ask, what tablets are you on? I just tell them and then they'll advise me as to what to take. (OP 1)

Experiences that affect medicine taking
There were multiple factors that could impinge on the older person and person with dementia’s motivation to achieve their goal of safely taking the right tablet at the right time.

Fear of dependency
Fears of dependency were not due to the perception that drugs were additive, rather it was about the reliance for good health. The GP was attuned to this fear.

But no I don’t like taking tablets. I don’t — [it’s] not the taking of them, I just don’t like to be dependent. (OP 11)

We feel resentful I think. I do. I resent having to take them. (OP 11)

So there is this real ambivalence about wanting to stay healthy but not being reliant on tablets. (GP)

Fear of ageing and ill health
The GP also proposed that medicines were symbolic of ageing and ill health, and in turn there are some variable responses from the older person participants in reference to this. For some, tablet taking began late in life, perhaps reinforcing the idea that increasing age and ill health are related.

I think there is an attitude and an expectation really, that people want to live well until their final days and I think they see medication symbolically as a sign of their vulnerability or illness or even impending death. (GP)

Because as you get older particularly – I notice with myself – I’ve got a lot less energy and I’ve got a lot less get up and go and instead of thinking, well, that’s because you’re 83, I think to myself, can it be such and such a tablet or should I not be taking those and I tend to question the tablets more than I’d probably need to. (OP 11)

I never took any medications till I was about 83. (OP 6)

Side effects
But for many of the other participants, medicine taking behaviour was affected by the fear of side effects and this was reinforced by this community nurse who was able to draw from clinical experience:

I don’t believe you take many, because you get a clashing. I have a fear that they start clashing and you get this poison effect. (OP 3)

They can still articulate that, no, that makes me feel sick. I don’t want to take it. (CN)
**No immediate therapeutic benefit**

The therapeutic benefit of a medicine provides another motivating factor for taking medicines. Older people, people with dementia and family carers measure benefit by reduction of symptoms, without this there appears to be a perception that the drug is not working.

> It doesn’t make me feel any different when I do forget [to take] it, you know that. It doesn’t make me feel any better when I do have them either. (Carer OP 5)

> One of the common ones that I come across is that people won’t take their cholesterol medication. When we ask them why, they say, oh, I didn’t feel as if it did anything. (Pharm)

Health professionals recognise that older people and people with dementia will intentionally decline to take the advised medicine, but exploration of the underlying reason for this decision is limited and usually only described in relation to the resulting behaviour such as refusal or discarding the medicine.

> There was some medication she was on, something to do with her blood ... but she was supposed to have two a day. But she was adamant that she was having one. Two upset her and she was not going to have more than two. That wasn’t a cognition issue. (CN)

> They go, oh well, sometimes I don’t take that [medication] because of whatever. (Pharm)

> It's not that they can’t take it. It's that they don’t want to take it so they keep chucking it away or something like that. (CN)

There were some prescribing behaviours by the GPs that ameliorated this and helped to provide the incentive to the individual to take their medicine. This included realistic and flexible prescribing and questioning the need for the introduction of a new medicine.

> I tend to try and avoid prescribing things for patients who aren’t going to take [them]. (GP)

> Is this medication really necessary? (GP)

Both GPs and pharmacists focussed on the benefits of a medicine to generate incentive for the medicine to be taken. One GP gave a good example in how they describe the incentive to take medicine in relation to treatment of symptom rather than the underlying disease:

> The essential basic reason for most of these things is to get them to continue taking it and to show that it’s of benefit to them. (Pharm)

> I think it’s easier to persuade patients to take a slightly less patient-friendly regime when they’re getting a direct measurable benefit to them in terms of improvement of their current symptoms from taking the medication. (GP)

> Just taking anti-hypertension as an example; if a person’s getting frequent headaches and I know beta-blockers may reduce the incidence of them, I might suggest that look we might try a beta-blocker because it’s cheap and it also may help you with your headaches. If the patient therefore takes it and they find it does work, then they’re going to be compliant because even though they’re taking it for the high blood pressure, that’s not symptomatic. (GP)

> You can follow up ... well did you feel better when you were on these? (Pharm)

It also included a process of educating the person to understand the long term benefits of the prescription, particularly when there were no immediate noticeable benefits of the medicine or where it may cause the patient to experience troubling side effects.
Sometimes the problem can be explaining to them that they need to take their medicines regularly even when they don’t notice any benefit. (Pharm)

So you can persuade people to take something that’s got potentially some side effects if they perceive how much more beneficial effect in terms of relief of a symptom. (GP)

Health professionals described an approach that utilised negotiation skills during the consultation or for a longer period to support the older person’s incentive to take their medicine.

I try to advise my clients that their medications are their unwanted friends; sure we don’t want them, but without them then they’re going to suffer. (GP)

Often you can do a bit of negotiation and say ... have you tried this or that, and cut down this medication and your costs could come down ... perhaps there is a newer medication that combines both these ingredients in one tablet. What do you feel about that? (Pharm)

He said take those for three months. The three months will be up soon. I'm going to ask him whether I should go on taking them, or ... I really feel better, but you don't know whether it's psychological. (OP 5)

Encouraging [medication] without forcing it on people, and if it doesn’t work straight away, you know, if you've got some experience you know to be patient. (CN)

The prescriber’s attitude appears to have some bearing on the person’s feelings to medicine; judicious prescribing is important.

I think I like them to be well trained and informative and show a bit of interest and I think both the chemist and doctor we’ve got have that. (PWD 6)

Well, he’s not the type of doctor anyway who would prescribe something just because it will keep the patient happy. (OP 11)

Easing the medicine administration process was also seen as crucial in encouraging independence in medicine management; this could be achieved through simplification of the regime.

So simplicity is a goal. (GP)

If you can simplify the regime, sometimes they can go along like that for a little bit longer. (CN)

So she’s changed the medication to a new drop that is once a day. (Carer OP 4)

The nurses have actually spoken to the doctor with regards to his medication at the moment, because at one stage he was on morning and night medication. Now it's all morning medication. (Carer PWD 7)

There was an increased awareness of the need to engage with older people and people with dementia to understand the underlying motivations to taking or not taking their medicines.

I think there needs to be or could be some direct action on trying to explore with people what is their current attitude to their health, to life and the pills. (GP)
Values and Beliefs About Medicines

Where the motivations and incentives to take medicines appear to emerge from the older person’s immediate experiences, it was evident that there were more deep seated values and beliefs, often formed at an early age, that subsequently influence medicine taking as an older adult. As with motivations, the health professional rarely asks the older person or person with dementia about their beliefs and values, despite the profound effect they can have on behaviour. Later, in chapter 6, health professionals describe the ways in which they determine a person’s medicine taking behaviours where the focus is on the person remembering to take the tablets, their understanding of the medicines and ability to dispense the correct dose at the correct time. This section demonstrates that, by exploring the older persons’ values and beliefs, it would become evident to the health professional how they should approach the individual’s management of medicine. It describes how a person’s values and beliefs were formed and what factors promote acceptance for the medicine.

The older persons themselves summed up the range of beliefs held with the following quotes:

- *I hate it.* (OP 6)
- *I'm not a tablet taker.* (OP 5)
- *They're a nuisance.* (OP 7)
- *I regard medicine as poison.* (OP 3)
- *I’d really rather take my chances and not take medication, but my doctor tells me that’s not a good idea.* (OP 11)
- *I wasn’t very well when I was around the 70 year old [mark] and I gradually got over that effects ... and I’ve been going well ever since and that’s why I say the tablets are keeping me going. I’m 87.* (OP 9)
- *As far as I’m concerned they're keeping me alive.* (OP 9)

The underlying sources of these values and beliefs for older people either came from previous interactions with health care professionals, parental influences, or economic influences.

- *[The doctor in Singapore] He said all medicine is poison.* (OP 3)
- *My mother wasn’t very keen on taking tablets.* (OP 5)
- *Dad very [seldom] went to a doctor ... His attitude was that he knew more than the doctors and he wouldn't go to them.* (OP 1)
- *Of course, we never had the money to go to a doctor. You never went to the doctor like they do now, for a cough and a cold.* (OP 6)
- *We never took our children to the doctor unless it was absolutely necessary.* (OP 6)

It was noted that situations arise where the person resists change to their medicine regime, but understanding the older person’s need to develop familiarity with the way tablets look, feel and are named is important.

- *I think there are issues, for instance, people [hate] their pills but when I try to reduce their diuretics they fight me or just ignore it and they’re even worse with benzodiazepines. Trying to get people off them is almost impossible; they are attached to them like glue.* (GP)
It’s very confusing for an older person especially that drugs have two or three names. (Carer OP 1)

Sentinel health events were the precipitating factor for acknowledgment of the need for medicines for some participants.

I wouldn’t go without it now that I’ve got this clot. (OP 8)

But for most, it was described as an adjustment to the need for medicine or acceptance of it.

Dr said I now declare you as a diabetic. Then she tried me first on a diet, because she could see my face, what medicine? No way. Now I am quite happy with it. (OP 3)

I feel that if you’ve got to take it you’ve got to take it. (OP 8)

I hate taking them and she hates taking them too but I said we’ve got to. (Carer OP 5).

Belief and values also included the faith placed in their health professionals and an understanding of the need to maintain continuity for effective treatment.

I am fine with the help that I get from my doctors. I know because they keep me alive. (PWD 5)

I believe strongly if you go from different ways and you listen to your doctor or go to another doctor and go to another doctor you’re in trouble. (OP 3)

But for others, there was also a respect ascribed to the GP that resulted in unquestioning acceptance of a prescription, which appears to be a commonly held attitude in this generation of older people that took part in these interviews.

You just had the doctor, and he said take those, and that’s what you have to do. You didn’t question it, did you? (OP 5)

We haven’t learned to question the same as the new generations are. (OP 11)

Natural medicines

It became apparent that for some older people, people with dementia and even family members who were interviewed, there were a range of beliefs surrounding the use of natural medicines. For one participant who had described conventional medicines as ‘poison’, his acceptance of a treatment for diabetes was actually influenced by the knowledge that the medicine was derived from a natural source. The incentive to continue taking the medicine was supported by three positive outcomes: it worked, he felt better and his food tasted better.

The nurse, she told me this [diabetes medication] is a derivative of French flower called a French Lilac ... So I said, this is a herb? It’s a herb extract and she described [it] to me, which to me is glorious. (OP 3)

The range of natural, herbal and complimentary medicines in use by the interview participants was largely limited to fish oils and omega 3, glucosamine and vitamin tablets. The reasons for taking these products were wide ranging, for some it was to increase energy or as a prophylactic.

They're just the two things that I think that might help me because I do athletics. It gives me a bit of energy I hope. (OP 1)

You know, when you think about vitamins, you think oh God, they'll make me jump around and make me good. (OP 5)
I've got arthritis and I take the glucosamine because I feel that it helps my arthritis ... I take the fish oil tablets because they're good for your heart. (OP 2)

For others natural medicines were considered when conventional medicines had not worked.

If you were desperate, and nothing else worked, you'd say ... that would be the time I might say yeah, I'll have a go at that. (OP 5)

I wouldn't be alive today if I didn't have them [herbal medicines]. (Carer OP 6).

Some participants not taking any natural medicines were open to the idea or simply curious, while others were fearful of them.

I wouldn't be against something if I thought it could do any good. (OP 5)

I'd be interested to know what they [herbal medicines] do, but I wouldn't be interested in taking anything like that. (OP 6)

I'd be frightened to death [to try herbal medicines]. (OP 5)

For the participants who reported to be taking herbal medicines the products were initiated through various mechanisms, some on advisement from their doctor, the media or through word of mouth.

The glucosamine was the doctor’s suggestion. (Carer OP 2).

Well, I do take vitamins, but that’s on doctor’s orders and it’s the vitamin D, because we don’t get in the sunshine like we’re supposed to. (OP 10)

They had someone on the Kerri-Anne show yesterday and they were talking about arthritis and they mentioned fish oil's very good and I thought to myself I'll buy a bottle of that fish oil just for curiosity. (Carer OP 5).

Just read it and it said they're supposed to be good for omega-3. (OP 7)

The cranberry juice was actually a friend, the cranberry tablet was a friend of mum’s who was down last Christmas, suggestion and that was after mum had had the urinary tract infection. (Carer OP 2).

Although not all participants were receptive to these influences:

I had friends visiting from overseas who said to me, you’re not taking any vitamin tablets and I said no. Why aren’t you taking — I said because I don’t need them. Oh you should be on vitamin E for this and — well they’re both dead and I’m still here. (OP 11)

It was recognised that for the consumer of natural medicine, there is a potential for lack of insight into the need to involve the GP or pharmacist with their choices.

Sometimes they’re taking other things that they don’t tell us about and some of them may be by their herbalist or whoever else or they’ve decided they’re going to get them from the chemist and they don’t even tell the pharmacist what they’re getting. (GP)

You're not quite sure ... what's it [the complementary medicine] for? Does your doctor know that you have it? (CN)

Health professionals were particularly concerned regarding the potential for adverse reactions which increases when additional medicines are used.

The more that people can access medications that maybe a generation ago would have been prescription, then I think there’s more potential for a lot more problems. (GP)
They like to use a lot of different natural therapies and so that opens up an even bigger field because then you've got to talk about the potential interactions and then you start having to look up alternative therapies too to see if they interact with their current medications. (CN)

The older person, person with dementia and family carer participant’s understanding of the importance in sharing their decision to commence a natural medicine with their health professional was variable, many describing themselves as ‘traditional’ or choosing to follow their doctor’s advice, others would seek advice from their GP before starting, and there were those who chose to use natural medicines as first line treatment under their own advisement.

Mum has been a more traditional medicine person who believes what the doctor says is the way it is. (Carer OP 2).

No, never use them [natural medicines]. The only tablets we ever use are what's prescribed by the doctor. (Carer OP 5).

I'll ask him about that [the vitamins] and he says, yes. Vitamins you can take. (OP 1)

I usually try complementary medicine first. But I don't impose my beliefs on anyone else. (Carer PWD 7)

There was some concern from health professionals that for some people, their use of natural medicines was driven by a negative perception of conventional medicines.

I think there is also a bit of a general suspicion that the medication probably isn’t needed; that we're all being duped by pharmaceutical companies whereas of course natural additional medication of course ought to be taken [sic] avidly. (GP)

But this concern seems to be unfounded in this cohort as it was clear that participants felt there was a place for both types of medicine and indeed, suggested that it was the health professionals that held the negative attitude toward such treatments.

There is room for all of it [conventional and natural medicine]. But it’s the medical profession I think is a bit frightened of them. Not all of them but there's quite a few that are frightened of it. Pharmaceuticals companies are. They're dead frightened of herbal stuff because they'd lose a lot of money. (Carer OP 6).

My personal belief is that herbal based medicines should be used by the profession. (OP 3)

Exploration of a person’s medicine related beliefs and values was not described as a formal process within clinical consultation; indeed for some GPs it was not a priority.

Does it formally enter the consultation? No. I think for me more semi-conscious ... in my view, very few consultations, particularly in general practice, have the luxury of attending to something that’s a fair way down the priority list. (GP)

Although, it was postulated that by using active listening skills it should be possible to establish when a person holds a specific belief or preference that affects their willingness to take the medicine. Participants also ensure they make strong beliefs known to the prescriber, by articulating it verbally or non verbally.

The quality of the response, if you're alert to the issue, will often determine or give you good insight into those who are unable[to take their medication] — there is a marker there as I mentioned — or those who are unwilling [to take their medications]. (GP)

He knows by my face that I don't want to take them. (OP 6)
**Relationship with Health Professionals**

On the whole, this group of older people described the relationships associated with their medicine management in terms of a team of two or three, that is, themselves, their GP and for some, their pharmacist. There was little need for other players to join in this dynamic and generally it was a stable relationship with clearly defined roles and responsibilities. Several important characteristics that contribute to the development and maintenance of a relationship are described. Trust and confidence were the principle qualities that could be fostered through the skill and knowledge of the health professional as well as seeing the person as an individual. However, it was determined that there needed to be a balance between the professional and personal relationship. Older people and people living with dementia identified that continuity was an important component to building such a relationship and many had developed strategies to enable this to occur. Information giving was also described as an important component of this relationship.

The development of a good relationship was advocated and this was articulated by the pharmacist as rapport:

> **Our doctor; yes you have much confidence in them but I found now with the chemists ... They’re tremendous — you can depend on them. They help you. They can help you and they do, yes. It’s a team isn’t it?** (PWD 3)

> **Well I think it's [the relationship with the Dr is] very important. I mean you should be able to tell him everything.** (PWD 7)

> **It’s the rapport you develop with a person I think, because they’re not going to open up unless they feel comfortable with you.** (Pharm)

**Trust and confidence**

Development of trust and confidence was largely dependent on the value that the older person and person living with dementia placed on the health professional’s experience, knowledge, diagnostic skills and familiarity with their health needs.

> **You must have confidence and I don’t believe in changing doctors or going to a clinic and have one doctor one day and another doctor that day. Because the idiosyncrasies of the patient must be known to the doctor.** (OP 3)

> **I think I like them to be well trained and informative and show a bit of interest and I think both the chemist and doctor we’ve got have that.** (PWD 6)

> **And our doctor ... he must have a mind like a steel trap because he knows, he remembers a lot about us, but he also knows what’s happening in medicine — what’s new.** (OP 11)

**Showing an interest**

People were perceptive to their health professional’s level of interest in them personally and as an older adult, and it is a characteristic that promotes confidence.

> **[The lady doctor] takes much more interest in you than he does, put it that way and I think she’s quite a good doctor.** (OP 8)

> **He’s always interested in what you’ve got to say or appears to be, and it gives you the confidence doesn’t it?** (OP 10)

> **I feel more confident about what he says, yes. He asks more questions, and things like that.** (OP 5)
**Being a friend and being a professional (conflict)**

Familiarity was a strong feature for older people, although this had an adverse effect when the older person perceived that the professional relationship extended to one of friendship:

> Yeah, our relationship with him is good. In fact the last — not the last time but the time before he said I like it when you two come in, he said I enjoy working with you. So, you know, we feel comfortable with him. (OP 11)

> I felt too comfortable with her, and she was more like a friend, so it wasn't good, to be truthful. (OP 5)

**Continuity over time**

Continuity of the relationship was an important factor to the older people participants. This relationship may be with the health professional or with a system such as the pharmacy (rather than the pharmacist). The older person participants described how they invested in a relationship with their health professional by attending the same GP or pharmacist at every visit, or the same practice or pharmacy over decades.

> I’ve been going to him — ever since he’s been [here] I’ve been going to him because I went to the doctor who was there before him. (OP 9)

> As far as the GP’s concerned I feel I talk to [my Dr] about anything and that's why I keep going to him. I won't have anyone else in that clinic. (OP 7)

> I’ve been going there — oh well, I’ve been in here since ’55 ... They know me. If I want to know I can go to the chemist and I ask them. (PWD 7)

This finding did not correlate well with the perception by community nurses that people tend to shop around, using different pharmacists and GPs to suit their need.

> If they're only using one pharmacy because of course a lot of them do shop around and use different pharmacies and they don't have a national register that registers all the medications that they're on. (CN)

Some of the general barriers to the development and maintenance of relationships were often due to resource issues such as availability of preferred GP resulting in long waiting times or having to see another professional.

> [He] was my doctor, or is supposed to be my doctor, but I can never get to see him. (OP 9)

> We do have [another] Dr. I’ve seen her a couple of times and she's always ... it's all on computer and she just gets it up on the computer and reads it. So she knows all about my history and when I’ve had the last prescription and that. (OP 1)

> He [the Dr] gets you in and out as soon as he can but he's very, very thorough. (OP 7)

**Giving and receiving information**

During this journey it emerged that the perceptions of the health professional in what information was required dictated how the older person responded to meeting this need. For many participants, information giving occurred at the GP consultation level and this was the preferred method. If this level of information was inadequate or did not occur then some participants would actively seek information from other sources. It appeared that there were a small number of participants who were more passive in this area.
**Information needs**

The extent of information needs regarding medicines were described, ranging from passivity, generally by people with dementia, to the older person participants actively engaging with their health professional as the medicine was prescribed or dispensed.

I don't bother them, asking more questions about it, I just am a good patient, I just take it. (PWD 5)

I don't know [how I find out about new tablets]. I just take the tablets. (PWD 1)

I always ask him why and what's it going to do and what side effects there might be. (OP 7)

Health professionals need to be aware of this diversity in information seeking behaviour, however, their perceptions about the level of information that older people and people with dementia need or have the ability to understand was centred on those who were more passive and did not appear to reflect the extent to which older people would go to gain this information.

Not wanting to take them and not being able to take them ... I think that those two often are difficult to tease apart because I think it’s sometimes very hard for a person to understand why they need to take something. (GP)

They don't care, don't want to know about it and you have to accept that as well. You know, if they're 80 or beyond, they don't want you to explain what the medication is for and the side effects, they just don't want to know about it. (CN)

The reality is most of them don’t know why they're taking the tablets they're taking. (CN)

The health professional also described a minimum acceptable level of medicine knowledge that a person should have when receiving a new medicine, this ranged from knowing why they need to take the medicine and the time that it should be taken, but perhaps should also include being able to recognise which tablet is treating which condition.

At the minimal level they need [to know when] to take it and at what time, so the mechanics is the minimum. (GP)

They can say oh, this one here, that's for my cholesterol. This blue one's for my heart. (CN)

The giving of information about the medicine as it was prescribed or dispensed was the preferred option by the health professional and sought by many of the participants.

They do, the pharmacists when you're going onto something new they always ask you have you taken this tablet before and I say no, so then they explain what you've got to do and everything. So that's really good. (OP 7)

However there were many variations on the giving and receiving of information, in this instance the GP gave the information but had little expectation of the person to accept and retain it as demonstrated by this older person participant:

My minimum level I know is a very low level. That doesn’t mean they shouldn’t be offered the other information. But if they don't want to know why I think they should have it, I'm okay with that. They'll generally be told it, but if they don’t want to remember it, that's fine. I know that's far lower than any standard would ever say they should have. (GP)

I just want to know — and usually it’s after the event. Something has happened and I think I wonder if the tablets are causing it. (OP 11)
Other participants describe situations where the health professional did not engage at all in the giving of information:

*No [my nurses don’t advise me about medication side effects]. (PWD 2)*

*I don’t think I got much education about it, just to say that you’ve got to take it. (OP 8)*

Older people participants described different methods in which they sought information about their medicines, this included the internet or reading the information leaflet enclosed with the medicine, although this option was not ideal as it gets thrown out or is not available.

*If I want to know something, I always say to our youngest [son], would you look it up on the internet for me. (OP 6)*

*About all I read on them is what are the side effects and how often should I take it. I don’t go into the chemistry of it or what the ingredients are. (OP 11)*

*There might have been a little thing inside it, but I’ve thrown it out. (OP 7)*

However, the preferred option appears to be a mixed approach of speaking to the pharmacist or GP and also being given a printout of the written information to which they can refer to at a later time.

*Every patient should be able to ask their GP to give them a printout [of their medications. (OP 2)*

*[The doctor] he'll tell me and then when I go down to the chemist he gives me [the pamphlet] but I can't read the darn thing. So I ask him and he tells me all about it. So then when I come home I put that in my little file in order of when I've got to take them. (OP 1)*

**Adapting to Compromised Ability**

The participants who were interviewed in the older person category were independently managing their medicines and had no major health conditions that caused significant functional disability. The people with dementia were in the earlier stages of the disease but were receiving some degree of support with their medicines management either from family or a nurse. These participants described a range of age related changes in their dexterity, mobility, and sight that impacted on the management of their medicine. This section also describes the ways in which they adapt to the change in capacity using routines and organisation techniques and closes with identifying how they would need to seek more help once these strategies fail to work effectively.

**Dexterity**

Dexterity in the context of medicine management is the ability to use hands and fingers to manipulate objects. Changes to dexterity were described by the older person participants in relation to the effect it has on their ability to handle the packaging and tablets, particularly if they need to be split prior to administration.

*Some of these people can’t open bottles but they can pop out pills; others the reverse. (Pharm)*

Packaging and containers were described to include bottles, the foil strips and the boxes they are packed in, as well as dose administration aids (DAAs)\(^3\). Commonly used DAAs

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\(^3\) Dose administration aids are defined as a device or packaging system where doses of one or more solid oral dosage forms of medicines can be organised according to the time of administration (Australian Pharmaceutical Advisory Council, 2006).
are the Webster-pak and the Dosette Box. The way in which impaired dexterity affects the utilisation of these are discussed.

The difficulties experienced with bottles were in relation to manipulating the cap:

The bottles ... once or twice ... have those children’s ... secure from children thing ... they are secure from adults at times too. (OP 10)

Well the new bottle of that ... you’ve got to press it down real hard to get it off ... if I screw it too tight and I put it back in the drawer I’ve got to struggle to get it open again because it’s childproof. (OP 9)

Multiple reports regarding the difficulty in dispensing tablets that come packed in the foil strips were made, with some participants describing how they transfer the tablets from the foil strip to a container that is easier to use on a daily basis.

Sometimes I have trouble with the inside. You can open the box all right but sometimes I have trouble getting it out. (OP 8)

I have a bit of a problem with the blister packs, trying to get those [tablets] they’re very tight and hard to get out. But it’s just a bit of patience required. (OP 11)

But I do find and I think anyone with arthritis would be in trouble because the blood pressure tablets, they take a bit of getting out. (OP 7)

Matter of fact I’ve taken to not using them at all ... I empty it into another container. (OP 10)

There appeared to be some evidence that the packaging for generic medicines were less user friendly and that changing to a named brand was one option to resolve difficulties but had a cost implication.

I can get them in a bottle if I’m prepared to pay for [it]. (OP 7)

Many of the participants chose to use dose administration aids to organise their medicines, yet in practice, changes to functional ability resulted in people experiencing difficulties with these. Many participants described problems particularly in removing the tablets from the Webster-pak and having to resort to mechanical means such as scissors and spoons to assist or opening the blister pack in an area (such as the bed) that aids the location of an errant tablet.

I can't press it down, so I just use a pair of scissors and just cut the top and out they pop (OP 6).

I don't like these blister packs very much, but I do it with a ... I usually get a little spoon and just push it out at the back. (OP 5)

I tend to sit on the bed so that when they pop the wrong way they go on the bed and I can find them easily. (PWD 6)

One older person was legally blind but maintained a high level of independence and safety across all aspects of medicine management although locating a dropped tablet causes some difficulty:

And the last one [tablet] flies away somewhere and I’ve got to sit down on the floor and I’ve got to rub my hands all over the floor so as to try and find it. (OP 1)
This interview participant also spoke of the way in which he relied on the packaging or on touch to distinguish between tablets, a strategy also used by others who found it difficult to visually distinguish tablets based on size or colour:

*Especially when they get down to the size of the aspirin. Very difficult to tell apart. So I've got to try look at the packet. Or even the packet will tell me what it is.* (OP 1)

For older people participants it was frustrating to drop a tablet but worth the effort to locate it. Splitting of tablets was also discussed but easily remedied using a tablet cutter:

*I can't find it [the tablet]. So I decided that I wet a piece of cottonwool and dab it onto the floor and I pick it up that way. If I can't find it, I think, did I sweep the floor?* (OP 6)

*We have a tablet cutter but that’s not all that accurate actually I don’t think. But if they’re scored it’s pretty easy to snap them, unless they’re very, very tiny.* (OP 11)

**Mobility**

Changing mobility, that is the ability to move about, does affect the person’s management of their medicine, largely reflected in their ability to access the GP or pharmacy to obtain a prescription. Different mechanisms were utilised to overcome this barrier which included taxis, asking friends with cars to help, use of the tablet delivery service or changing to a nearby pharmacist.

*[the GP surgery] arrange transport for me. I mean, she's the only one I have to do it with ... Even the specialist ... even [the] Hospital, where I have to go, they say, we'll ring and book your taxi.* (OP 6)

*Before I knew [my friend] I went up to the surgery by taxi. I had to go up there, because I don’t drive but I’ve now got a friend who drives.* (OP 8)

**Strategies to support self management**

Older people demonstrated a high level of self motivation in devising systems through which a medicine regime could be safely and correctly managed for oneself. Remembering to take medicines as prescribed was of paramount importance, and strategies to support this included linking medicines to a routine, through the use of visual and environmental reminders, use of aids and adaptations, third party prompts or through internal memory strategies. Being organised and use of dose administration aids also feature as a mechanism to support self management. Self management was not just described in relation to the actual process of taking the right tablet at the right time, it also included prescription management, and the elements that this consisted of were described.

**Linking medicines to a routine**

The most universal approach to support the taking of tablets at the right time was to link the time that the medicine was due with an existing routine, such as getting up in the morning, the first cup of tea, meals or retiring to bed.

**Getting up in the morning:**

*I take them ... generally when I’ve had my shower.* (OP 9)

*I do that immediately as I get up and prepare for the walk, I take that before I start the walk ... This one is when I go to bed and it's easy.* (OP 3)

**The first cup of the day:**

*I really just got into the habit of every morning taking them with my first cup of tea so that I never forget.* (OP 5)
As I make the cuppa I put the coffee and everything in the cups and take my tablets out and then take the tablets so I don’t forget it. (OP 7)

Linking with key events such as meals, a routine evident even when hospitalised:

I think it's establishing a routine ... Where is the best place to leave it so you're given the best chance possible ... that when they're sitting down having their meal, oh, lunchtime, I've got to take my pills. So there's a prompt. (CN)

Well I've always got them beside my breakfast bar and that's where I have my breakfast and that's when I take my tablets. (OP 2)

I lay it next to my food and then I say if it's only a one course meal I take one in the beginning of the course and then two thirds of the way down I get the second one. (OP 3)

When I was in hospital they used to bring them round before brekkie. I was only in there for a few days the last time I was in, so it didn’t matter. But even so they brought them round before brekkie and said, oh, take your pills. Which I’ve always done. (OP 9)

As a part of the bed time routine:

Then I take one at night, and I always have a drink before I go to bed, so I take the tablet then. (OP 5)

Usually when I’m going into bed. If I’m going to clean my teeth I think I’ll take them now because they're in the bathroom. (OP 8)

A smaller but still significant number of people describe using visual and environmental reminders as ways to promote a reminder to take their medicine.

No [I don't forget any], because I put that on my breakfast tray when I make it up at night and I set the tray. (OP 6)

I do have them sitting right there and if I’m having coffee after dinner that reminds me (OP 11)

I'll leave it there so I remember them of a morning and I remember of a night. When I get my meals ready, I can't help but see them. (PWD 8).

I take them there [in the bathroom] and I don’t forget them then. (OP 8)

Use of aids, adaptations, and the environment

People living with dementia reported that they used external memory aids such as notice boards, distinctive containers and colour to provide the cue to take medicine.

Got a noticeboard as well with little reminders. (PWD 5).

I've got a different style container for the tablets. (PWD 6).

I've got a little pepper pot or something like that in the drawer ... I put them all in there and then I know I’ve got to take them with a glass of water. (OP 9)

The nice bright yellow top on top of your fridge and you see it. (PWD 5).
Third party prompts and reminders

The use of third party prompts and reminders were suggested strategies by health professionals but none of the older people reported that they used professional carers or the phone as an aid. If a third party was used it was generally a spouse or family carer.

There could be some expansion that ... health and community care providers could be allowed to prompt regarding medication. (GP)

I suppose the other ridiculously resource-intensive option would be phoning people. (GP)

[My husband] will nudge me periodically and say do you remember — did you take your tablets? (OP 11)

Memory

Older people participants tended to rely purely on memory to manage their tablets more than any other group, although one participant was legally blind and was dependent on this approach.

[My husband] doesn’t [rely on visual prompts] too much. [He] relies on memory more. (OP 11)

I put it in my mind; I’ve got a pretty good memory. What I do is, I can put it in my mind of when I’ve got to take them, what tablets I’ve got to take and when I’ve got more to take. (OP 1)

Being organised

Being organised with the medicines was a significant approach for older people and people living with dementia due to the importance they ascribed to their medicine.

I try to be organised with it, yes. (OP 9)

Not only was organisation of medicine reflected in the way in which people linked tablet taking to their daily routines and other strategies but also to the way in which they used dose administration aids, the refilling of these either personally or at the pharmacist and the way in which they organised the management of their prescriptions.

We would either consider a dose administration aid — and that would be the first option. (Pharm)

It was recognised that the way in which people organised their medicines could hinder their ability to self manage their medicine.

I think the way people organise their medication, if they’re not using a Dosette or Webster-pak is another barrier. (GP)

Self-devised system

There is an increasing range of dose administration options available to people, some described systems that they had devised themselves using small containers or jars.

What I’ve done is I’ve got a tray in there and I’ve got them in order. The one at the front is two tablets. One on the left is in a little plastic container. (OP 1)
**Dosette box**

The use of the pill box or Dosette box was described but required a system to ensure they were replenished on a regular basis and without error by the individual using them.

“[A Dosette box] that’s marked breakfast, lunch or dinner and then on the back I put a list so that I know when to replenish it — what I need to put in.” (OP 11)

**Webster-paks**

Blister or Webster-paks provided the most universally accepted method to organise medicines, providing confidence and transference of the responsibility for filling them with the right tablets to the GP and pharmacist.

“What’s made such a difference to me is the Webster-pak. It’s just at the right time for me and I feel safe as houses.” (PWD 3)

“I don’t go to the chemist now. From the doctor they get that thing, what I need [blister pack]. That goes to the chemist and they send me [the blister pack].” (PWD 7)

Introduction of the Webster-paks were generally advised by the health professional based on their knowledge and understanding of the person’s ability.

“The doctor just thought it would be easier for me [to have a Webster-pak], he said, [the pharmacist] will make them up for you. He said, it’ll save you worrying about anything.” (OP 6)

It was evident that there were some limitations associated with the use of blister or Webster-paks indicating that these are not a panacea for everyone. Quite apart from the issues associated with dexterity as described earlier, other problems included the confusion associated with the number of blisters on a card when only using a one a day dose, and the additional cost associated with them.

“For once daily medications] perhaps they should have packs that just have just Monday without itemising which time and without all of it being divided up into little sections.” (Carer PWD 4)

**Prescription management**

Organisation was also important for the management of repeat prescriptions; the aim was to ensure that the tablets were not allowed to run out.

“I think you’ve got to be really organised about scripts if there’s lots of medication.” (Carer OP 2)

“I like to know exactly what I’m taking and then if I miss something or I’m running out of something I know exactly what I’ve got to get.” (OP 1)

Prescription management appears to be a convoluted procedure that includes four processes: identifying which tablets need refilling and when, getting a repeat prescription authorised by the GP, filing the prescription at the pharmacy, and collecting it. Keeping track of when tablets needed renewing and when a new authorisation of the prescriptions were due were important to avoid the last minute realisation that tablets were about to run out. By using the same pharmacist it was possible for the older person to hand the management of the prescriptions over to the pharmacist.

“All my prescriptions are kept at the chemist and when I want them I just go down and say to the chemist I want x number of x type of prescription and they prescribe it, they give it to me.” (OP 2)

“This pharmacist ... he puts a note on the tablets saying this is your last script.” (OP 11)
Others preferred to maintain control and devised routines and systems to enable this to happen:

*I used to have to go and have to see the doctor. Now I just ring through and they either post it to me ... I said, you can post it to me, instead of posting it to the chemist.* (OP 6)

As described earlier, limitations to mobility either due to age related changes or inaccessible transport options may restrict older people’s direct access to the pharmacy, for some the solution was simple:

*I said do you think somebody could deliver my tablets for me when they're ready. They said yeah and the young girl brought them up.* (OP 2)

**Changing ability and needing help**

Knowing when it was no longer safe to self administer medicines and when to seek assistance was discussed, with forgetting or confusion and subsequent increased risk to self being identified as the precipitating factor.

*You start saying, oh God, have I taken those tablets? Have I not? If you just take them any old time, I would be lost if I did that.* (OP 5)

*I would make that decision myself [to seek help with my medications]. I feel as though I would because if I start getting confused and muddled up with my prescription then I'd say, well it's about time I got somebody to help me.* (OP 1)

*I think while there’s two of us we would take over from each other probably.* (OP 11)

*So if I got to the stage where I couldn't open bottles and tablets, yeah, I'd be in a bit of trouble then.* (OP 7)

*I suppose if you’ve got to that stage where it was worrying you to have somebody come and help you.* (OP 8)

*But if you get worse, you need help, don’t you? I wouldn't be against using them [Webster-Pak].* (OP 5)

**Loss of independence**

Often changes in health or supports represented a loss in the ability to independently management of health and medicine needs:

*That could be aggravating for the patient, because they lose enough independence as they get old without having someone take over their lives.* (OP 11)

*It's loss of independence and loss of your confidence to be able to do things for yourself.* (OP 7)
Summary

The responses from the older people, people with dementia and family members indicated that the motivations and incentives as well as the values and beliefs that each individual holds regarding medicines may have a significant impact on their medicine taking behaviours. Equally, participants provide some enlightenment as to what can ameliorate some of the factors that could affect adherence to a medicine, such as the older person participant who found the natural basis of his diabetes treatment to be congruent with his beliefs. If the GP understood how the individual is driven by their motivation or belief, perhaps they could alter their prescribing behaviours accordingly to provide the incentive to take medicines. It also provides an indicator that if the person ceases taking the medicine it gives the GP the basis to go back and explore what has changed. It behoves the health professional to look more closely at how their own behaviours and attitudes may affect the person’s medicine taking behaviours.

These older people and people with dementia participants provided profound insights into the efforts they take to develop an effective medication team and the value they place in their relationship with their health professional, particularly the GP and pharmacist. They described a vast range of strategies to support safe self medicine management in the face of age related changes to functional ability.
The self-medicine management strategies identified have the following implications for the assessment tool:

<table>
<thead>
<tr>
<th>Personal Resources for Medicine Management</th>
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<tbody>
<tr>
<td>- Ascertain the person and/or family carer’s goals for medicine management</td>
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<tr>
<td>- Ascertain the person and/or family carer’s expectations of their medicines</td>
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<tr>
<td>- Consider the person and/or family carer’s experiences of the use of medicines</td>
</tr>
<tr>
<td>- Look at how the person and/or family carer feels and is responding to their medicines</td>
</tr>
<tr>
<td>- Explore if the person and/or family carer has any concerns regarding interactions of medicines with prescription, over the counter or herbal medicines</td>
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<tr>
<td>- Explore beliefs and behaviours around complementary health measures (diet, exercise, physiotherapy) and desire to lessen the need for tablets; if the older person has an interest in this</td>
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<tr>
<td>- Explore the person and/or family carer’s stance on natural medicines, if yes, have they advised their GP</td>
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<tr>
<td>- Ascertain who the person and/or family carer’s chosen health providers are and if they have difficulty accessing them</td>
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<tr>
<th>Medicines Information</th>
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<tr>
<td>Explore how the person and/or family carer obtains information about their medicines</td>
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<tr>
<td>- Identify the person and/or family carer’s preferences regarding how information is to be presented</td>
</tr>
<tr>
<td>- Ascertain the type and amount of information the person and/or family carer wants and in what format (verbal, written, language needs)</td>
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<tr>
<td>- Identify the person and/or family carer’s preferred source of information regarding medicines</td>
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<tr>
<td>- Find out if the person and/or family carer use iPhone or similar applications or would like access to electronic resources</td>
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<tr>
<th>Capacity/Making Medicines Manageable</th>
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<tbody>
<tr>
<td>- Identify what strategies the person and/or family carer has that support medicine management</td>
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<tr>
<td>- Ascertain the confidence of the person and/or family carer in administering medicines</td>
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<tr>
<td>- Observe the organisation of medicines</td>
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<tr>
<td>- Explore whether the person and/or family carer has experienced problems handling medicines</td>
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<tr>
<td>- Explore whether the person and/or family carer has experienced difficulty in identifying medicines (either by name or appearance)</td>
</tr>
<tr>
<td>- Explore strategies that may assist administration of medicines</td>
</tr>
<tr>
<td>- Observe storage of medicines</td>
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<tr>
<td>- Find out if the person and/or family carer would consider the use of a dose administration aid</td>
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4. Something Changes

In the previous chapter, older people and people with dementia described the elements that support self management of medicines. The reasons for seeking and accepting more help were based on how the older person participants felt they would recognise they were no longer able to cope with their medicines. Changing cognitive ability was identified as the key factor, and family carers of older people and people living with dementia were able to substantiate this. In this section, family carers provide a more extensive picture of the indicators that change the status quo and threaten the person’s ability to maintain systems that enable self management. These include changing functional and cognitive abilities of the older person or person with dementia. It also includes having to manage the transitions between environments such as hospital and respite, or the medication changes associated with other prescribers such as hospitals and specialists. Variances to prescriptions, names and appearance add to this changing landscape. Even where these changes were presenting themselves, older people were still trying to adapt, often with a graduated involvement of the family member. As the person was no longer able to adapt to these changes it appears that there is increasing involvement of other health professionals. The decision to seek help from other service providers was a complex one, often as a result of many factors, predominantly safety. The need to keep the older person and person with dementia involved in their own medicine management processes was evident and family carers described a number of considerations to facilitate this.

This chapter identifies the factors that contribute to the transition from self management to needing more help. It outlines where the person’s adaptation to age related changes, as described in the previous chapter, can no longer sustain independence. It will be discussed using the following headings:

- Changing ability
- Environmental factors
- Encouraging self management
- Decision to seek more help
- Who provides the assistance.

**Changing Ability**

There were many considerations required of the prescriber before issuing a drug and the ability of the individual to take this medicine as prescribed was a key factor. The person’s ability to read, understand and act on the information relating to the medicine that the doctor prescribed for a health condition was important.

*There is no point having wonderful health services and wonderful GPs all on the ball and the whole thing sort of unravels because the patient is unable to follow the instruction.*

*(GP)*

**Cognitive function**

There are many influences that can alter the person’s ability to manage their medicines over a period of time. Family carers were most cognisant of the indicators that alerted them to the need for more support. These would include forgetfulness that led to tablets not being taken despite the use of the reminder and organisation systems set up by the individual.

*She is inclined to become a little bit forgetful at times.* *(Carer OP 5).*

*The reason my sister and I got together about it was because she wasn't taking her medication.* *(Carer OP 6).*
It was all right in the beginning to actually just give mum this [Dosette box] and she could manage it. But now what I’m finding is, as I said, there’s tablets may be left in. (Carer OP 2).

Decline in cognitive function was generally associated with short term memory loss, cognitive impairment and dementia, all of which can impair an individual’s understanding of the need to take medicines, ultimately impacting on adherence.

The cognitive problems often lead the person to not being motivated to take them because not only do they not even remember, but don’t even remember why they need to take it so they don’t want to take it, even with all the best efforts in the world by the GP to explain why something might be needed. (GP)

He doesn’t know what each [tablet] is for. (Carer PWD 1)

So in a sense, any patient that has any cognitive impairment would act as a trigger for a district nurse who happens to be going in for some other reason to maybe raise that issue with the GP … But I think the GP may not have considered it if there was no particular … if they don’t see the cause for concern because they may not have done a home visit. (GP)

Nurses felt they were well positioned to investigate cognition concerns:

As soon as you start talking to them you sort of just … yeah, you do a mini-mental because at least you can pick up some cognitive issues and I can’t see a pharmacist doing that. (CN)

Well, then the pharmacist would probably ring the doctor and say look, I’ve just had Mrs Smith in. She seems a bit forgetful lately. Have you noticed anything? And then the doctor might say, yes I have, or, how about we do a home medicine review? Let’s have a look what she’s doing at home. And that would then set a train of events in place that might identify a problem. (Pharm)

Other alerting factors were changes in behaviour such as refusal to take medication or cessation of tablets without informing anyone:

Occasionally now she does say no I don’t want to [take tablets]. That’s rare and I think that’s her dementia progressing or she feels sick or there’s something going on. (Carer PWD 3)

It was actual changes in her behaviour at different times. Then I realised that I had to know that she was taking them. (Carer OP 2).

My main problem with my mother was she would take half of the tablets and it would take me another three or four hours to try and get her to take the rest. (Carer OP 6)

See, I’m not sure whether Alzheimer’s plays a part in it, but now every now and again he’ll say to us that he doesn’t need it [the medication]. (Carer PWD 7)

She does do that at times; I’m not taking them today. (Carer OP 5)

She [mum] had seen on TV or heard on the radio that taking aspirin wasn’t good for you in terms of blood thinner, so she had stopped it without telling me without telling anyone. (Carer OP 2)
Disorganisation and dropped tablets were other indicators, often resulting in missing tablets and prescriptions.

*She was misplacing prescriptions.* (Carer OP 2)

*Quite often you’d say to her, did you have your medication? After a while we found out she was just putting it from the container or the packaging that they were in or we would put them into one of those tablet pack things, monthly things, she would take it out of there and then put it into something else.* (Carer PWD 8)

*What she did was to keep going to the tablet box and keep taking the tablets all the time. By the time it got to about Thursday there was nothing left.* (Carer PWD 1)

Failing to take medication was also an indicator for one family carer that her mother had delirium:

*The only time she didn’t [remember to take her tablets], wasn’t doing that so well was when she had the infection and that, she went quite loopy.* (Carer OP 2)

### Functional ability

Changes in the person’s ability to handle medicines resulted in the use of DAAs, but it had not resolved the difficulties, with dropped tablets still occurring when the person attempts to use the Webster-pak or Dosette box as described by this family carer.

*Mum can sort of do it and they can pop, so she’s more likely to throw them out of this. With the slide one she’s more likely to leave them behind.* (Carer OP 2)

*But it’s her hands are worse and a bit more sort of arthritic I find she’ll empty it out quick. She’ll leave one in, drop one on the floor and because she’s a bit deaf she doesn’t know she’s done it. So I think it’s not as simple as just giving it to mum.* (Carer OP 2)

### Swallow

In the following chapter a family carer describes the issues surrounding the management of a PEG tube for a relative who lost the ability to swallow.

*The other thing that can be a barrier to taking medication is swallowing difficulties ... They tend to not want to take the really big tablets if they’re having trouble swallowing.* (Pharm)

*She has some swallowing problems so quite often we get a bit of a choking and a bit of a coughing fit.* (Carer OP 1)

### The emotional experience

The emotional impact of changes is an individual one. This family carer described how her husband tried hard to compensate as his ability to take medication deteriorated, but the recognition that independence was no longer viable resulted in distress:

*He was very defiant about the fact that he had taken his medication and then he was very embarrassed when he found he hadn't and being a very intelligent person he then struggled very hard for a very long time to try and cope. So it was like him swimming in a big sea.* (Carer PWD 2)
Environmental Factors

It became apparent that there is a need to look beyond the changing ability of the individual and consider the impact that the social and physical environment has on medicine management. When managing medicines it is evident that factors such as multiple prescribers, changes in the names and appearance of medicines as well as transitions between hospital or respite and home should be considered.

Multiple prescription sources

As the health needs of the older person and person with dementia change, it was more likely they come into contact with multiple health professionals. This increased the potential for prescriptions to be issued from different prescribing sources. As will be described in chapter 6, these health professionals tend to work in ‘silos’ (in isolation from others).

*If we were to use a simple definition for medication management being something like the process for monitoring the journey between prescription and consumption or something like that, then the system failure occurs at the prescription end because there are multiple sources of prescription.* (GP)

*The drugs that the nurse ultimately is confronted with may have come from various sources and one source doesn’t necessarily know about the other.* (GP)

*You have so many people under different specialists and no one really communicates very well.* (CN)

*I suppose the other thing that perhaps comes into this argument a little bit is perhaps particularly when there’s multiple prescribers all having a clear idea of what the goals for treatment are.* (GP)

Changes in drug names and appearance

It appears that as the persons self management ability changes and the family carer begins to provide more support, the changes in drug names, the number of tablets to be taken and their appearance can cause some confusion.

*I think even the change of drugs, the names and how it’s opened up now to all the different names is a major barrier, even to nurses, knowing what tablets they are ... So no wonder the elderly have difficulty knowing.* (CN)

*Probably when you are listing the medications, you should call it Reboxetine. But in fact the script will say Edronax. The script will say Stilnox, but the box will say [Dormazole].* (Carer PWD 2)

*The tablets themselves even change shape from one to another.* (CN)

*Recently our chemist was taken over by a chain ... and they changed the name of just about every medicine that we take. So where I could pick up the tablets in the dark and tell what by the feel and the size and the glossiness of it now I’m relearning it all because they’ve changed the name of just about every medicine.* (Carer OP 1)

Reaching an agreement or standardisation of drug names was viewed to be the most effective way of overcoming this situation.

*I suspect we should have an agreement that drugs be called, for example, drugs be called by their generic ... by the actual ... we need consistency.* (Carer PWD 2)

*If the chemists and the manufacturers are going to change the brand name all the time, then why aren’t we all using the proper name?* (Carer OP 1)
Hospitals

However, it is not only the person’s changing ability that influences safe self medicine management. External factors such as transitions between hospital or respite and home and the increased number of people in the medication team, particularly other prescribers can also impact on medicine management. Inherent in managing changes to medicine regimes is communication between the person and family carer, and prescribers.

*Medication that they give as a result of my visit to the hospital, they usually notify the doctor. They send a letter to him.* (OP 1)

On the whole, hospital initiated medicine changes presented challenges for older people.

*Someone you see who’s come out of hospital one or two weeks ago and is overwhelmed with what's happened and what they've heard. They don't know what they're on and they're just like, I'm lost.* (GP)

*Sometimes they do change them a bit when you go into hospital.* (Carer OP 5)

People living with dementia were particularly susceptible to movement in and out of hospital and respite as the inflexible institutional medicine practices rarely allowed for self management, resulting in the loss of ability to follow a once familiar routine.

*The habit of taking medication every day, the habit of her remembering to take medication every day had been broken and I didn't know how it would start up again.* (Carer PWD 3)

*It has actually taken a week actually for him to remember [the routine].* (Carer PWD 2)

For one participant, the consequence of a hospital initiated change to a person’s medicine was greater than needing to learn a new drug. It caused them to question why a change was necessary and potentially influenced the relationship and trust that they had established with the GP:

*When she was in hospital they actually changed what medication she was on. I think that can harm their confidence in your own doctor too. They don’t know whether the doctor was right or whether the hospital was right.* (Carer PWD 4)

For the most part, changes in medicine regimes made as a result of a hospital admission were generally problematic to all members of the medication team. From the GP’s point of view these were often not reported in a timely manner necessitating the ‘patient’ having to provide the information, not an ideal situation from the doctor’s point of view. For the community nurse it created difficulties, as medicine administration could not be initiated without authorisation by the GP.

*They’ve come back and I don’t know what the hospital’s done in relation to their medications and I’m thinking what do I fill out here?* (GP)

*Sometimes there is a delay. If I go and see the doctor first I'll always tell him what they've put me on.* (OP 1)

*Sometimes the patients says they've stopped the yellow ones and they've put me on some green ones and I think I don’t know, what’s the green tablets? I have no idea.* (GP).

*So the task that the nurse confronts is to decide (a) what is needed; what is necessary, so she may have to contact the GP but the GP may not know what the hospital has given because often on our medical director we will have drugs there which have not been deleted, so if she contacts the GP they may not really be reflecting what is sitting on the kitchen table.* (GP)
Communication of changes to medication was an issue for the older person and their GP. The individual was given little explanation and their GP could not expect to receive information in a timely or consistent manner.

[I was given] paperwork to say what tablets I was taking, that was all — but they didn’t say why I was taking them or anything. (OP 9)

Quite often their discharge summary doesn’t get to the GP til they've been home for a couple of weeks so you contact the GP to try and clarify admission and you can’t. (CN)

It seems that there are systems within systems whereby the communication of discharge medicines varies according to which part of the hospital system the person is exiting, some had systems that worked better than others.

But from the public [hospital], it seems that both the pharmacist and the discharge summary are expected to include, like send them independently. Which is good, because at least then that means one of them comes. (GP)

I'm not quite clear in sub-acute whether it's meant to be the person writing the discharge summary or the pharmacist. Or perhaps it's given to the patient as well. We not infrequently don't get a copy. Or if it is, it's hidden amongst other stuff that's I'm sure very relevant for a rehab admission, but blindingly unhelpful for the medical care of a person. (GP)

To support timely and effective communication of medicine issues it was suggested that it be given priority on the discharge information and include the rationale behind the medicine change.

But from our point of view, if the drugs could be in flashing lights on the front page, and on the second, the reason for any changes, that would be a very helpful thing. (GP)

One of the other problems is when people come out of hospital there's a whole lot of things that no one knows what the thinking behind them is. (GP)

Respite

Movement in and out of respite introduced another level of complexity, especially for the family carer, particularly as Webster-paks have to be organised, which may not coordinate too well with the systems that the individual has devised to manage the medicine when at home.

If I got ill and my husband would need to go into respite care for that time, so I've approached some people and they've got forms that you have to fill out and get the doctor to fill them out because they say that they're not allowed the handle the medication. So it has to be organised by the chemist into a something pack [Webster-pak]. (Carer PWD 4)

He has been in [respite] for three weeks and that always gets me out of whack, because they have to go into [Webster] packs for them. (Carer PWD 2)

A spousal carer for her husband with dementia took the initiative by booking respite for herself and maintaining the continuity of the medicine administration by giving them herself.

[When we go to respite together] I say, you look after my husband but I always do our medications, they don’t take over. (Carer PWD 1)

The inflexibility of the medicine systems also extend into the day care environment as reported here:
If you go down there [to the day centre], they don’t let you take medication yourself and they hold it with a time to be given. (Carer PWD 5)

Encouraging Self Management

Where it was evident that a person’s ability to manage their medicine was changing, often accompanied by environmental changes, some family carers described the ways in which they encourage the older person or person with dementia’s continued involvement in the process: by leaving a small number of tablets from the overall prescription to self manage, by using a set routine, taking a supervisory approach or by advising the person what they were being given.

So mum can still do that routine. She’s quite ... and she’s also able to replicate it when we go down to the holiday house. (Carer OP 2)

I put them in a little medicine vial for her and she takes them with a glass of water sitting over there on that chair. (Carer OP 5)

I tell him every time I'm giving it [medication] to him, what it is I'm giving him. (Carer OP 3).

When she got sick or had a chest infection a while ago, then I made sure I’d go over and say to her have you taken your tablets or if I’m there I’d give them to her. (Carer OP 4).

I've got to remind her sometimes — don't forget you've got to take your tablets; because I take tablets myself too. So if I remember to take mine, I think instantly then of hers and then she takes hers too. (Carer OP 5)

Dose administration aids were an important strategy for supporting independence as well as maintaining safety when one had not been used previously. These were often advised by the pharmacist but the correct use of these were generally overseen by the family carer.

It was the pharmacist that told me the best one to use [Webster-pak] ... Obviously he knew what tablets she was on and how often she took them and what her eyesight was like. (Carer PWD 3)

It said M, T, W, the days of the week in big letters so if mum didn’t have her glasses on it didn’t matter; she could still see an M, even if she knew it was Mondays. (Carer PWD 3)

It worked for a couple of years. (Carer PWD 3)

Community nurses were also keen to support the older person and person with dementia to maintain independence and remain involved in their own healthcare for as long as possible. Community nurses described how they encouraged this by gradually reintroducing self management strategies with the individual and monitoring progress closely over a period of time.

So it could be like a graduated thing, so you would perhaps try them with daily support and then pull that back, maybe a week or two later, when there’s evidence of [medication management]. (CN)
**Decision to Seek More Help**

The consequences of the observed changes in a person’s ability were measured in relation to the risk that incorrect use of medicine may have on them. For example, for this daughter it was her perception of the ‘seriousness’ of the drug Oxycontin—an opioid analgesic—a justifiable concern echoed by the GP.

> Because Oxycontin is such a serious drug and it really matters if she gets it wrong. I mean previously to that she’d been on cholesterol drugs and in depth things whereby it wasn’t ideal if she got it wrong but it wasn’t that serious; it wasn’t going to kill her. (Carer PWD 3)

> Unplanned unsafety, so people either taking the wrong doses, not taking them, or taking things erratically. It’s a particular problem with some things like warfarin or insulin, less of a problem with other drugs on the whole. (GP)

This daughter describes how her fears for her mother’s safety were fuelled by the media attention to the death of an actor that involved Oxycontin:

> I guess with an Oxycontin tablet I had the fear of God put into me because Oxycontin at the time was in all the [media] ... it was about the time that [actor] died and Oxycontin, in my mind it was a trigger drug. Oxycontin, what! She’s on that. (Carer PWD 3)

The daughter’s decision to seek more help with medicine management for her mother was triggered by three factors: the drug related death of a media personality, the perceived dangerousness of the drug, as well as her mother’s pain and deteriorating cognitive state increasing the times she forgot to take her tablets

> Oxycontin had the potential to do a lot of damage if she got it wrong. (Carer PWD 3)

> Her not taking her tablets really [triggered] referral to RDNS. At first she was taking them every time and then it sort of degraded. She took them most times. Then it degraded a bit more and she took them sort of okay but not really that often. She was getting worse as time was going on. (Carer PWD 3)

> Also, the pain was making the dementia worse too. She was in serious pain. (Carer PWD 3)

**Who Provides the Assistance**

As demonstrated by the family carer of the person with dementia, the decision to seek help could be quite complex, involving multiple considerations about the person’s ability, safety issues and the level of risk they were willing to expose their relative to. The provision of help with medicines came from two main sources, either the spousal and family carer or from a nursing service. Awareness of how to seek help was limited. Here the family carers describe their increasing involvement and how more help is sought from the community nursing service when multiple visits are required throughout the day to give multiple medicines.

> So I think that as mum’s got older I’ve had to be more involved. (Carer OP 2).

> I get them all ready for her every day. (Carer OP 5)

> That meant then that she had to have it [the medication] every day, which meant that someone had to give it to her every day and I’m not available every day and if I get sick what’s going to happen? So that’s when we got the district nurse to come in, but they only come in Monday to Friday and I do it on the weekend. (Carer OP 4)
For the family carer, sharing the medication visiting with the community nurse also provided monitoring of health and wellbeing.

When she had her assessment done the lady who assisted suggested we get the Royal District Nurse out to do the medication. That was one less job that I had to do. ... Then once I thought about it I could see why as well, while the district nurse was going around they were also monitoring mum and picking up things that they could see. (Carer PWD 8)

It has relieved us a bit knowing too that the district nurses are coming in not just to give mum the medication but they have a little chat to her and they make her a glass of Sustagen. (Carer OP 4)

**Summary**

There were numerous circumstances that resulted in the older person and person with dementia being unable to sustain safe self management of their medicines. It become increasingly apparent that changes to cognitive function that result in short term memory loss and alterations to the person’s usual medicine taking behaviours were the strongest indicators for needing more support. Other signs were disorganisation of medicines and difficulty handling tablets even when DAAs were in use. Other contributing factors were from the social and physical environment, such as involvement of multiple prescribers, changes in names and appearances of medicines and transitions between hospital or respite and home. As the individual was no longer able to adapt to their changing ability, there was increasing involvement of the family carer. There was a point where it was deemed that medicine safety could no longer be supported, often as a result of multiple precipitating factors. This triggered the family carer to approach the medication team for help.
Factors that result in changing ability and capacity to manage medicines have the following implications for the assessment tool:

<table>
<thead>
<tr>
<th>Access to Medicines</th>
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<tbody>
<tr>
<td>- Find out if the person and/or family carer is still able to access health care providers (GP, Pharmacist)</td>
</tr>
<tr>
<td>- Ascertain what help is needed to access to health care providers</td>
</tr>
<tr>
<td>- Ascertain who collects prescriptions or what strategies could enable collection of prescriptions</td>
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<table>
<thead>
<tr>
<th>Personal Limitations (Functional and Cognitive Ability)</th>
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<tbody>
<tr>
<td>- Observe for physical limitations with taking medicines (difficulty opening lids and packaging, poor vision/reading the label, dexterity, unable to administer inhalers/eye drops, swallowing, cannot hear verbal instruction or cannot understand due to language barrier)</td>
</tr>
<tr>
<td>- Observe organisation and storage of medicines</td>
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<tr>
<td>- Document experiences of any difficulty with remembering to take medicines</td>
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<tr>
<td>- Note changes from pre-morbid behaviour</td>
</tr>
<tr>
<td>- Identify components of your medication management that may be causing difficulty (e.g., prescription management)</td>
</tr>
<tr>
<td>- The person and/or family carer’s ability and willingness to use DAAs</td>
</tr>
<tr>
<td>- Ascertain the emotional experience of taking medicines</td>
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<table>
<thead>
<tr>
<th>Environmental Limitations</th>
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<tbody>
<tr>
<td>- Find out if the person is a frequent user of hospital or respite services and, if so, if continuity of prescription medicines is a concern</td>
</tr>
<tr>
<td>- Explore the communication of medicine changes</td>
</tr>
<tr>
<td>- Explore the multiple sources of prescription; the adequacy of communication between providers</td>
</tr>
<tr>
<td>- Ascertain if the person and/or family carer perceives the medicine regime as being complicated (in relation to changes in drug names and appearance, frequently changing doses, medicines with high risk of side effects, drug interactions)</td>
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<table>
<thead>
<tr>
<th>Support Network</th>
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<tbody>
<tr>
<td>- Explore the availability of family carer support</td>
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5. Family Member Advocacy and Carer Role

As described in the previous chapter, the medicine safety of the older person and person with dementia becomes compromised, resulting in a graduated involvement of the family member until they become the carer. The nurse is likely to become involved at this point either to supplement the family carer’s role or to replicate their role when the person lives alone and has no carer. As an increasing number of health professionals become involved the family carer also assumes an advocacy role, not only to support their relative’s medicines beliefs and values but also to uphold the goal of medicine safety. The established relationships that were described in chapter 3 change and the existing medication team has to adjust to the presence of the family carer and the expectations this new role brings. The family carers found their new role had quite an impact for them as individuals and they, too, found they needed to be in possession of certain abilities to sustain medicine management on behalf of another person. They also describe a range of strategies and support mechanisms that they found helpful, many were similar to those identified by the older person in chapter 3, but the components associated with prescription management appeared to be of significance to the family carer. This chapter will discuss the following:

- Advocacy
- Expectations
- Impact of the caring role
- Carer ability to carry out the role
- Carer medicine management strategies
- Factors that support carer role.

Advocacy

Advocacy is described as the support of an older person or person with dementia who has difficulty interacting with their health professional and having their opinion listened to. Advocacy, in the sense of medicines management, includes upholding the person’s values and beliefs regarding medicines as described in chapter 3. It also extends to the strategies that family carers undertake on behalf of their relative to maintain safety.

Family carers advocate for their relative based on their premorbid beliefs regarding medicines, their wish to remain at home and how this affects their willingness to take tablets.

*I'm healthy and why am I taking this stuff? Even if I miss a day or two, it doesn't matter. It's not going to kill me. That's his attitude.* (Carer PWD 7)

*Mum would always say, even before I got involved, mum would always say do I really need to take these?* (Carer PWD 3)

However, trying to uphold these beliefs on behalf of another person is often very difficult and requires some degree of compromise.

*I ask the GP that constantly [if mum can stop her tablets] and the answer is always no.* (Carer PWD 3)

*I guess because mum had been on some form of tablet for a long, long time, if she didn’t want to take them she would’ve stopped taking them long before I got involved.* (Carer PWD 3)
But it is clear that having to address these issues does create some angst for the carer.

_I think it's just something in the mind. I really do. She gets a thing in her head and says I'm not taking them today. So what am I to do?_ (Carer OP 5)

Family carers also reported having to advocate on behalf of their parent or spouse because of a health professional’s negative attitudes towards the older adult and nihilistic attitudes to dementia:

*Then I found out that Ebixa, we couldn’t have them both on the free medication, so that’s when I changed doctors because he said, because of [my husband’s] age, what’s the point.* (Carer PWD 6)

*One of the things that makes me so mad is that some GPs have got a view that because we're old we don't need quality health care.* (Carer PWD 1)

*The problem was, we had a GP at the time who didn't really want anything to do with aged care and we happen to be ageing. He also refused to work with the specialist that I wanted him to work with.* (Carer PWD 2)

**Safety**

It could be construed that family carers also adopted an advocacy role in relation to safety. Maintaining medicine safety was first introduced as a goal by the older person participants and subsequently sustained on their behalf by the family carer. Indeed it became a shared goal to all who became involved in supporting medicine management.

*The big responsibility [for safe medication management] is either on the patient or the person caring for them, because they're the ones administering.* (Carer PWD 4)

*Because the other day when my doctor increased one of my wife’s tablets, he doubled the quantity of it or the dose, the chemist actually came out and said to me has your wife had this level before? I said no the doctor has just increased it ... So he was aware that there was a difference from what she’d had before to what she was having this time.* (Carer OP 1)

It was noticeable that health professionals entered into a partnership with the family carer to maintain safety. The pharmacist took an active role to notice and communicate any potential for errors and the GP would optimise the medicine regime.

*Mum had a very good pharmacist ... Because if she saw something or she would say to me, if there is anything wrong she would ring me straightaway.* (Carer PWD 8)

*My worry was not to over medicate her and certainly not to under medicate her. So in 10 years working with our GP I feel we've got a balance — a good balance — of the medication.* (Carer OP 1)

*The GP and I talk about the balance ... So it’s a bit of a team effort which works well.* (Carer PWD 3)
**Expectations**

The medication team that was initially established by the older person and person with dementia then had to incorporate additional team members. This changed the dynamic of the team, the relationships and the expectations that each team member had of the other, particularly as the person who was central to all of this had become displaced. Whilst all team members spoke of their expectations of the other during their interviews and focus groups, it was not evident that this was formally explored in practice.

**Expectations by the cared-for person**

The people with dementia were able to clearly articulate some of the medicine related tasks that they delegated to their family; these included accompanying them to the GP and remembering the instructions given at the consultation, collecting the prescription from the chemist, and monitoring the medicine.

> Whatever he [the doctor] tells me [my wife] is aware of. If I forget it she'll remember. She's my walking memory. (PWD 6)

> Yes, he knows all my tablets and he always keeps checking on me now and again and checks on my tablets to see that I've taken them. He knows when I've taken them and if I've forgotten one or something, he'll know. (PWD 8)

**Expectations by the health professional**

The presence and support of a family member for some people, whilst not always available was regarded positively by the health professionals:

> But the majority of times [I] wouldn’t see a family member. (GP)

> Well we'd always try to encourage them [family] to be involved. (CN)

> I think we do try to get other family members involved because it’s crucial. (GP)

> One of the best ways is really to have them come in when you’re actually seeing the person, which most of them do when they start to get demented. (GP)

Although the health professionals did show some awareness of the limitations on families to take up the carer role:

> I think there's a lot of people [carers] who, if the week had another couple of days, they would do more with mum or dad. But it doesn’t and hence, they can't. (GP)

> There's often issues of ... say the children are working. They're probably 40s, 50s and they're all working. Who's going to get the scripts and who's going to pick up the medications? (CN)

Family were regarded as an important part of the care process and as a means of gaining information on a person’s history and management of their medicines as well as an important means of communicating with the GP and the person they are assisting.

> They might come in and say look I’m picking up scripts for Mrs. Jones ... oh how’s she going? ... But that’ll happen occasionally, but it’s not ... there’s no system for bringing people together. (Pharm)

> It's really helpful if family members can be present at that first admission to have to share about what they do and when they're available, and to hear what we're saying to the person that we're admitting, particularly if they do have memory problems, because it doesn’t get passed on. (CN)
Assumptions

Health professionals made an assumption that family members have a degree of insight into their relatives health needs and will accurately share medicine related information:

The son hadn't had any insight to what their dad was actually capable of — and through conversation you could tell the dad really didn't have the capability. (CN)

[You] rely on the family member ... assuming that the family member is going to pass that correctly to the patient, but you don’t know that that happens. I mean some are. (Pharm)

GPs identified that family involvement in their relative’s care may lower the doctor’s attention to medicine related issues, making the assumption that issues will be communicated:

Sometimes I think there’s a kind of relief that somebody’s taken it over and you presume that they’re doing it as carefully as you would like it to be done and unless they tell you that there’s a problem — you know dad can’t swallow tablets; he spits that out every morning or something like that — it’s almost like you don’t actively look or I don’t as carefully look for problems with the relatives. (GP)

[My dad’s GP] he said oh your dad is lucky because he’s got you, because he said, I know you are going to come in here and tell me as soon as something changes. (Carer OP 2).

Family carers’ expectations of their health professionals

It became evident that the relationship within the care dyad was particularly important to the family carer; this situation generally appeared to present itself when the GP was conducting a consultation with both the patient and the family carer present. Successful management of this situation was measured by the doctor’s ability to be inclusive of both parties.

Obviously she asks mum, “where’s your pain?” but anything to do with management or choices, and sometimes there are choices, she speaks to me. That works well. I’m not getting second hand knowledge. (Carer PWD 3)

I now go to 95% of mum’s appointments with her, if not, nearly 100 really ... He talks to my mum, like he talks to mum, but then he’ll turn around and say ‘what do you think’ or ask questions about how Mum’s been. (Carer OP 2).

As proposed earlier, community nurse involvement also increased at the point that poor medicines safety had been suspected or recognised. Referral was generated at the request of the family carer, or by the person’s GP where there was no family carer. Family members’ expectations of the nurses were varied, from assisting in the dispensing and giving of the medicines several times a day, to a daily check that the medicines have been taken.

‘Mum needs her pills four times a day’, you know, ‘we expect the nurses to do it’, sort of thing. (CN)

If they’re doing well with their Websters and then you say to the client and family, look we’re going to cut back; we’re going to come just three times a week, or something. Oh but who’s going to check on Mum every day? (CN)

The nurse’s role was also related to more than the medicine, it also provides a mechanism to reduce carer stress through monitoring the person’s wellbeing and to direct the person onto a service that could provide longer term monitoring and support.

They [the nurses] would say, we’ve given your mum the medication, she was still in bed, but they’d pop back later on to make sure that she was okay, if that was okay. But I had a very good relationship with the district nurse. (Carer PWD 8)
It’s more of a monitoring service that people might be after, not necessarily — the person might be more than capable. But they’re worried that because the family aren’t visiting every day … the family are worried that there’s nobody checking on their family member. I’ve come across that quite a few times. (CN)

Whilst family members were keen to have the nurse visit, this was not always shared by the person receiving the service. The ability of the health professional to develop trusting relationships is important.

Clients are often reluctant to accept our care because family members have instigated it. (CN)

She didn’t want people in her house. (Carer OP 4)

It gives her something to look forward to as well for the day — you know for the days I don’t go there. (Carer OP 4)

**Impact of the Caring Role**

The role of the family carer in supporting medicine management for a relative should not be underestimated. The family carer participants described a view of the caring role that was remarkable by the fact that they develop strategies and support mechanisms that enable them achieve medicine safety, not only for their relative, but also for themselves. Furthermore, it was clearly evident that whilst health professionals were appreciative of the family carer’s presence, they do not address their needs within the medicine management continuum. As described earlier, there was an expectation by family carers that health professionals would include them as part of the care dyad, but it may possibly be dependent on the individual relationships that are built between the family carer and their health professional.

Yes, she’s aware of the stresses associated with being a carer as well as my normal health issues. (Carer OP 1)

If I wasn’t being treated by that doctor, if I had a different doctor, would she be sympathetic to my carer role? I don’t know. (Carer OP 1).

Multiple causative factors of stress and burden in relation to managing medicine for another person were raised, for some, it was the inconsistency of the health care system when obtaining medicine or the complexity of the regime.

It is actually coordinating all the bits and then sometimes they [the doctors] will write you three months or four months or five or six. But there is no consistency to it. So, unless you monitor it and watch it carefully yourself, you are going to end up running out of things. So, I have developed all these little systems that overcome some of those things and this is one of them that has helped a great deal. (Carer PWD 2)
Carer Ability to Carry out the Role

Given that the family carers of older people and people living with dementia are spouses or adult children, considerations regarding age related changes to physical functioning apply equally to them as previously described by the older person participants. Changes to dexterity resulted in difficulties with opening packaging such as bottles, tablet foils, and blister packs were described, but as these issues are no different to those described in chapter 3, they will not be repeated here.

One task that was unique to a family carer was the preparation of medicines for administration via a percutaneous endoscopic gastronomy (PEG). This one carer found that the mortar and pestle hurt her hands, requiring her to find ways to overcome this. Equally frustrating for her was the response from the pharmacist when issuing medicines for administration via a PEG:

So I've got the mortar and pestle here but that was hard on your hands, crushing everything, pushing down on that. (Carer OP 3)

I just let them [the paracetamol] sit there for a second or so in the water then that crushes down really well without hurting. (Carer OP 3)

Information needs

It was identified that family carers need a period of education to enable them optimally manage their relatives medicines; the health professional’s response to this need was variable:

Then when someone else takes over I’m not sure that we always consciously manage to either re-educate them about why these were started in the first place and what they were all for, to the same level that we did when they were introduced to the person’s regime in the first place. (GP)

I certainly haven't been educated by any of the doctors other than the specialist, who has been very good. (Carer PWD 2)

The doctor. Yeah, [tells me] exactly what they are for. (Carer OP 5)

The pharmacist will, when I go in to collect the prescriptions, will say, now this is for your husband and she goes through what's written on it. (Carer OP 3).

Family carers also utilised the same mechanisms as the older person and person with dementia participants to obtain the medicines information. These will not be described as they replicate those discussed in chapter 3.

Carer Medicine Management Strategies

Family carers may not have anticipated the medicine role and from the reactions of health professionals, it appears that there are few formal or structured mechanisms for providing education and support. The motivating factors for undertaking this medicine role was not explored during the family carer interviews, but for one carer, a beneficial outcome for ensuring medicine was taken was described as:

When you take your medication you’re a lot easier to live with. (Carer PWD 7)

Learning to be a carer and to provide medicine support to a relative does not occur formally. Instead, family carers describe drawing on skills developed through their lifetime and a problem solving approach:
I think I'm lucky in a way, that I've been able to use experiences that I've gained along the way and to put them into practice now. I think a lot of people are not able to do that. (Carer PWD 1)

They wait for the doctor to give them their next scripts and they are always running out of scripts. Well, that seemed to be what was happening for me with mine and it was certainly happening with [my husband] and I just stood back from this and thought well, what do we need to do? (Carer PWD 2)

Likewise, not all family carers found they had innate carer skills, instead describing a process of having to adapt and cope with change:

I don't know why [she would pick out the tablets]. What I've learnt in this thing, you've got to be patient. You cannot afford either to get upset. (Carer OP 6)

Whilst family carers were strong advocates for their relative’s medicine related values and beliefs, they also recognised when medicine taking behaviours were related to the health condition or situation and described how they overcame these situations for the best interests of their relatives health and wellbeing:

No, he never objects because he doesn't really have any option to be quite honest. But I tell him every time whatever it is I'm putting into the [peg] tube (Carer OP 3)

I can remember my grandmother, the only way that my aunt could get to take her tablets was to crush them up in jam each morning, because she just was resistant to taking tablets. (Carer PWD 4)

If he [my husband] says to me, I don't want to take these pills. I say, well if you don’t want to take them I will throw them out but you know that they are going to do you good. (Carer PWD 9)

It’s always been at night [that she refuses tablets] and she’s always been more than happy to take them the next morning. (Carer PWD 3)

The importance of maintaining carer health was only briefly touched upon, either in relation to the need to maintain the carer role as described here or in relation to the concern of what would happen to their relative if they were no longer well enough to be a carer. This will discussed in chapter 6.

That’s right, I had this pain, I got home from Christmas lunch, got on the internet, looked up [the tablet] and I saw side effects, muscle aches, pains, joint pain. I stopped taking it. Within a week all the joint pains and aches and pains had gone away. (Carer OP 1).

Developing systems

In a similar fashion to the older person participants in chapter 3, family carer participants described the systems that they develop to assist them to safely and effectively manage the medicine on their relative’s behalf.

Yeah, so I think in terms of management, it’s having to be really I suppose extra efficient and develop a system. (Carer OP 2).

I've turned it into a routine. You have to do because if you get all willy-nilly, you get all mixed up yourself. (Carer OP 6)

Linking medicines with routines and use of environmental cues was used.

You do need to have them [medication] in one place. I think that's important to have them altogether. (Carer OP 3)
Organisation of medicines were also similar to the older person participants who self managed their medicines. Some family carers relied on their own systems, rejecting the pharmaceutical packaging and transferring the tablets to their favoured containers. 

I don't [use a pill box] for myself. I've got them all in a big jar and if I take one I put that aside and then get the next one out of the jar and do it that way and it works perfectly. You can't forget to take one. (Carer OP 5)

But more popular than the older person participants who self manage were the use of DAAs. Dosette boxes were favoured by family carers who liked to manage the medicines themselves.

I think where very early on I just had too many medications and it was all new to me. I just found that that [the Dosette box] was the easiest way to do it. (Carer OP 1)

In contrast, Webster-paks were not as popular with family carers as they were with people with dementia, largely because this system does not provide the flexibility for adjusting medicines.

They did say that they could put them in blister packets but that’s not necessary at this stage. It might be later on, but it is not necessary now. (Carer PWD 9)

You do make little subtle changes sometimes you know, instead of giving that tablet for breakfast you give it at lunch because you discussed it with the doctor and we’ll try that tablet at lunch. Well you don’t always document those things so when you go to your Webster-pak sometimes they’re strictly as the medical plans says. So you’ve got to be a little bit careful that your med plan that you give the doctor or the chemist is right up to date. Otherwise whatever you’re trialling is going to go out the window. (Carer OP 1)

Thinking ahead

Family carers also described how they have to think ahead when the person requiring medicines is away from home, this requires medicines to be prepared in advance.

I’ve got another little lot that I carry in my bag in case we’re caught somewhere or something, you know, goes wrong. (Carer OP 2)

If we’re going anywhere that needs medication, I crush it up and I’ve got a little screw cap plastic little container to just take it with us. (Carer OP 3)

Prescription management

Organisation was also important for the management of repeat prescriptions, particularly for family carers who often had to simultaneously manage their own as well as those of the person they were supporting. The aim was to ensure that the tablets did not run out.

I think you’ve got to be really organised about scripts if there’s lots of medication. (Carer OP 2)

I keep all mum’s scripts here, all her repeats, so I know where they are with mine. (Carer OP 4)

So we use the six-weekly visits to control the supply of prescriptions and then the seven-day kit pack to control the supply of medications from the pharmacist to us. (Carer OP 1)
Family carers were more likely to take into account the time that it takes to refill a script and the consequences of not being organised.

*Otherwise what could happen [if I wasn't organised], what did happen was we would get up to the pharmacy. I'd get half of what I needed and then I find half of it is not there. It was such a waste of time and it was also inconvenient. I was back and forth up to the pharmacy.* (Carer PWD 2)

Family carers were particularly grateful for any assistance with this process:

*So anything that anybody else can do is fine with me. Yes, absolutely. Once I'm aware of it and it's set in place.* (Carer OP 3)

Family carers spoke at length about their experiences of keeping track of when tablets needed renewing and when a new authorisation of the prescription was due to avoid the last minute realisation that tablets were about to run out.

*Another concern is keeping track of the prescriptions.* (Carer PWD 4)

It was evident that family carers found the prescription management processes more intrusive than the older person participants. Many different ways of managing this were described: highlighting the issue number on the prescription, by advance planning, and most appreciated was the collaborative approach by the pharmacist who would offer a reminder.

*I was often not sure how many scripts I had left, three. So I put these little circles on it.* (Carer PWD 2)

*They [pharmacist] put a big sticker on them to say this is your last repeat and it means I have to go down and get a new repeat.* (Carer PWD 6)

*When I am on the last repeat they will just say, 'you need to get more scripts from the doctor'. So it's all well organised.* (Carer PWD 9)

*I just go in [to the Dr's] with the note that the chemist hand me and just walk into the surgery. The girl says yes. Look, another script here and it's all done.* (Carer OP 6)

Variable experiences regarding the ways in which new prescription authorisations were managed by the GP were voiced. For some, this process was seamless and did not always require an appointment with the doctor if nothing had changed, for others, the consultation visit was a useful opportunity to review the medicines together.

*[The GP] he's been great because when he runs out of a script I can just ring up and then I'll go and pick up the scripts, and take them to the chemist.* (Carer PWD 7)

*They [doctors] organise them and they let the chemist know when it's ready and they send a person up for the script. I don't have to worry about it.* (Carer OP 6)

*We do a review of all the medications and then she [the GP] calls up her plan on the computer while I’m there. I have my list of what I’m short of and we go through and she either agrees or disagrees that I should be short of that. So yes there’s pretty good control from the GP.* (Carer OP 1)

Other family carers found the process a little more difficult, resulting in the use of written prompts to ensure the right medicine is authorised and checking that the prescriptions issued correspond to those requested.

*I keep this piece of paper and I put down the actual scripts that I need for strengths, frequencies and any comments that I have and I just find when I get there I'm not fussing around.* (Carer PWD 2)
These days they put them through the computer, a very good system. It spits it out. But you have got to make sure that they actually give you all the ones you want, because if you haven’t checked that you get away and find that you thought you were getting such and such and you’ve come away without. (Carer PWD 2)

Where an authorisation for a new prescription was not required, liaison was usually only with the pharmacist. Some people prefer to hand the task of identifying need for new prescription completely over to the pharmacist, whilst others preferred to maintain control and devised routines and systems to enable this to happen.

So all our prescriptions are now kept at the chemist. Which is really good, I find that excellent and we just ring up and they’ll have them ready and we can just pick them up. I find that to be a very good thing. (Carer PWD 6)

Now they are keeping the scripts down there and then every month they will just deliver to me or just tell me when it is ready and I will go and get it. (Carer PWD 9)

Working directly with the pharmacists has its pros and cons, with one family carer frustrated by the loss of a prescription by the pharmacist and another reporting the benefit as the pharmacist was able to issue an emergency supply of tablets:

We’re probably a little more wary [since our pharmacy changed] because I’ve had two prescriptions go astray, which has never happened before. We’ve run out of two lots of medication and when I’ve gone to order them I haven’t had a script. (Carer OP 1)

One of us had misplaced scripts, couldn’t find anything. Ran out of tablets. I went down to my local pharmacist and said, this is the story. He was able to look up the records and he gave me a small amount of each until I could go to the doctors. (Carer OP 2)

Some family carers were able to describe their experiences of having the community nurse involved in the medication team. They also provide a reminder mechanism for tablet refills, although the annual requirement for the doctor to authorise the nurse’s involvement was a little frustrating.

They [the nurses] rang me up one day and said, look Mum’s only got a couple of days’ medication left. (Carer OP 4)

I used to have to supply a new direction from the doctor every 12 months, for the district nurse to do it, but I think they do it between the district nurse and the doctor now because I’ve not had to do it and I’ve checked one day and sure enough, it was a brand new one so they must do it directly with the doctor, I think. (Carer OP 3)

The last task associated with prescription management is fetching the tablets, which, as identified earlier, can be problematic for people who have limitations in mobility or access to transport, or those who can only visit the chemist while the person they care for are in bed.

We're lucky we live in an area where we can get medication, we can go to the chemist every day of the week, but there are a lot of people who can't do that. A lot of people haven’t got a car. (Carer PWD 4)

If I have to leave the house, I leave the house when [my husband is] in bed. (Carer OP 3)
**Factors That Support the Carer Role**

Factors that support coping are largely described in relation to the role of the family carer providing support to a relative. Family carers were particularly appreciative of the opportunity to be able to discuss concerns surrounding their caring role and responsibility of another person’s medicines.

- Our GP is terrific. She's very, very good at ... if I'm worried about anything I can just put it in front of her. (Carer PWD 1)

- When I found it [Reminyl] wasn't working well enough I just said to the doctor, is there any scope for increasing that? She knew exactly what I was talking about so that's the way I do it now. (Carer PWD 1)

GPs who were responsive to concerns or were willing to collaborate with other health professionals were valued, as was the working relationship between the health professional and the family carer that was based on mutual respect.

- If she's worried about anything she will investigate it further. She just doesn't leave it sit. (Carer PWD 1)

- But he [GP] was willing to talk to a specialist. He was willing to do a home visit if necessary. He was willing to have me ring and say look [my husband] is not well. But I need some scripts, could you right out such and such, nothing has changed. (Carer PWD 2)

Flexibility was another factor that would support the medicine management relationship. This was reciprocal, the GP who was willing to make a home visit and the patient who is willing to see a different doctor on occasion.

- He is wonderful and of course he comes to see [my husband] now because [he] can't walk that far. (Carer PWD 9)

- I've decided that it's a bit difficult to get [my husband] up to the surgery now, so the doctor's willing to come here so he comes here and I'll just have my list with me and he was happy to fill them in. (Carer OP 3)

Other factors that support coping were discussed, such as being organised and working together with other family members to provide the care.

- My sister lets me know everything that's going on. My sister also helps out if I'm away for a couple of days. (Carer OP 6)

**Continuity over time**

As with the older person participants, family carers preferred continuity in their relationship with their health professional:

- We've been with our GP for what? Must be about eight or nine years now. (Carer OP 5)

- Then we've got that personal relationship with that one chemist. I think that's a big advantage. (Carer PWD 4)
Summary

As identified from chapter 4, the family member’s role insidiously changes into that of a carer as the person’s ability to safely self-manage their medicines diminishes. The key component of this role has been described as advocacy: upholding the person’s premorbid beliefs and values and implementing the strategies that supported ongoing safety. It was noticeable that there was an inequity in how the family carer was treated within the medication team. Where the self-managing older person and person with dementia were central within this team, family carers acting in this advocacy capacity were not afforded the same level of partnership. Health professionals were able to identify this imbalance, describing the appreciation of their presence, but also recognised their failure to provide the education and support in return. The family carer participants clearly articulated the impact of the care role and the factors that supported or hindered their ability to perform it. Many of the strategies to support safe medicines management for another person were as described by the older person and person with dementia participants in chapter 3. However, it was clear that family carers had to be more organised with some tasks such as prescription management due to time restraints and they tended to be more assertive with health professionals to ensure their voice was heard within the medication team. Health professionals need to take note of these factors that support the family carer.

The factors that influence advocacy and the family carer role have the following implications for the assessment tool:

<table>
<thead>
<tr>
<th>Advocacy</th>
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</thead>
<tbody>
<tr>
<td>- Identify the goals for medicine management with the person and/or family carer (ensuring goals are based on their own values and beliefs or substituted judgements are based on the wishes and beliefs of the person who is being cared for)</td>
</tr>
<tr>
<td>- Identify supports needed to maintain medicine safety</td>
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<table>
<thead>
<tr>
<th>Carer Role</th>
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</thead>
<tbody>
<tr>
<td>- Explore if the medicine management role is burdensome</td>
</tr>
<tr>
<td>- If burdensome, what components of medicine management cause difficulty and why</td>
</tr>
<tr>
<td>- In what areas might the carer benefit from help, to relieve or minimise this stress and burden associated with medicine management</td>
</tr>
<tr>
<td>- Identify supports needed by the carer to keep functioning in this role</td>
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</tbody>
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<table>
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<tr>
<th>Nurse as Proxy Carer</th>
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<tbody>
<tr>
<td>- Identify what strategies have been used to manage the person's medicine so they can be replicated and other strategies added where necessary</td>
</tr>
<tr>
<td>- Explore how the older person/person with dementia wants their health needs coordinated by service providers</td>
</tr>
<tr>
<td>- Work with the person to discuss options for care that address their needs (for example, discussing what interventions could address those needs)</td>
</tr>
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</table>
6. Locus of Control and the Medication Team

It was evident that once the older person or person with dementia was no longer able to adjust to their changing ability as discussed in chapter 4, the number of people involved in supporting medicine management increased. These people are described as the medication team and include the individual, their family carer, GP, pharmacist, practice and community nurses, and other prescribers. As the risk for medicine error is perceived to be increased for the individual, the health professionals respond differently and ‘take control’. What we see emerging is that the older person or person with dementia is no longer in control of their own health care; they appear to be sidelined.

Whilst the family carers and health professionals share the same goal, that is, maintaining safety, the motivations for achieving this are very different. As identified in chapter 5, it appears that the family carer acts in an advocacy role to keep their relative involved in the medicines processes. This chapter will describe how health professionals were motivated by duty of care and compliance with legislative and regulatory requirements for the safe administration of medicine. It describes the assessment processes that occur when concerns for medication risk have become apparent. The roles, relationships, communication processes and organisational systems within this medication team are described, as are the factors that appear to have the potential to support or hinder the successful management of medicines.

This chapter will explore:

- Control
- Working as a medication team
- Assessment
- Barriers to team work
- Developing collaborative relationships

**Control**

In some way, this chapter is based on issues of control; of who has ownership of which task or the professional responsibilities to the medicines and the person taking them.

*There’s the issue about who controls what drugs they’re on and the confusion, if you like, that’s medically systematic within the clinical in terms of the roles adopted and how that single patient’s agenda is owned by several people. (GP)*

Control was also viewed in relation to legislative and regulatory frameworks that the health professionals are required to work with, yet translation of these into practice can have positive or negative impact on the older person, person with dementia and family carer.

*There is this apparent need to control and have reporting guidelines and I can see where that has developed but it is actually making things worse ... all the reporting from data gathering and information gathering I think is actually interfering now with motivated people actually trying to do good for the patient. (GP)*

*It is not that you can’t cope. It is just that all these things are so difficult and they are so messy and you are limited by pharmaceutical restrictions, doctor’s restrictions, pharmacist’s restrictions. (Carer PWD 2)*
**Working as a Medication Team**

It has been espoused that successful medicines management can only occur when the individual and their family carer are central to the process with health professionals working collaboratively, in other words, person centred medicines management. There are many factors that contribute to the success or failure of a team.

Work teams are groups whose members work intensely on a specific, common goal, using their positive synergy, individual and mutual accountability and complementary skills. In a work team the combined individual efforts of team members result in a level of performance that is greater than the sum of those individual inputs. (Robbins, Bergman, Stagg, & Coulter, 2005, p. 504)

Family carers and people with dementia were able to perceive the health professional’s capacity to work as a team. Where collaborative relationships existed, participants felt reassurance and confidence with the systems in place to support medicine management and the family carer described themselves as being inclusive to this team:

> The chemist has taken working with your doctor and that’s quite reassuring. (PWD 3)

> There’s the GP, there’s the pharmacist, there’s the case manager. There are the various carers that I ring, there are the people at the day centre and there’s RDNS and there’s me. It’s a group effort. (Carer PWD 3)

**Understanding each other’s roles and responsibilities**

As identified, for successful team work it was important for the team’s members to understand each other’s roles and responsibilities. It was evident that the participants had established this, with the GP described as the gate keeper, the pharmacist as the expert of drugs and the nurse having the observational skills to ascertain the persons functioning in their home environment.

**GP as gatekeeper**

GPs described themselves as gatekeepers, channelling and co-ordinating all medicine related decisions through to the rest of the team.

> The GP is the compiler of this information and so the buck stops with the GP deciding whether all the hospital medications etcetera are relevant or not ... but in the end I think the GP does have to coordinate the prescribing end of the medication and the nurse should work with them. (GP)

> The GP is obviously the primary healthcare provider, so it is logical that they are in control over it all. (Pharm)

**Pharmacist as expert on drugs**

There was a general consensus on the role of the pharmacist, where their expert pharmacological knowledge and computer systems could be utilised to monitor the safe use of medicines:

> The pharmacists are the appropriate people to look at the range of drugs. That’s what they’re trained to do in an academic discipline. (GP)

> The list that GP thinks that they’re taking is not what the person’s taking. They don’t know about all the things in the kitchen cupboard that I see when I’m sitting at their kitchen table (Pharm)

> The pharmacist that's dispensing should be looking at the pharmacological issues. (CN)

> You get a lot of information looking at the pharmacy dispensing history ... to see how regularly they’re getting their [prescriptions] filled and things like that. (Pharm)
Nurses’ observation skills

The nurse’s role was best described by the GP as having the capacity to observe the person’s ability to safely use medicines in their home environment and communicate this back to the medication team.

I think, given that the district nurse actually attends the house and looks at the drawer, for instance, of pills is probably the best placed person to actually make sure that prescribed tablets or medications going in the mouth, in consultation with pharmacists and GPs who may then have to work on re-evaluating the whole regime if it is just not workable. (GP)

We have to check for those things. Often that's when we find there's all sorts of problems, and the doctor doesn’t really know that they're on this, or the pharmacy thinks that they're on two [lasix] and he says cut it out. (CN)

An emerging role for the practice nurse\(^4\) was evident, although their place within the medication team is constricted by the GP expectation that collaboration will not occur outside of the GP clinic environment.

So practice nurses are going out to do home visits for health assessments — part of GPs management plans and so on — and one of the things they do is they look at medication. So you have, in effect, another professional in the same discipline that may also be highlighting medication problems. (GP)

But they [the practice nurse] go out as an agent of the doctor and so there wouldn’t be a mechanism for them to then interact with RDNS; they have to bring their findings back and then we have to do the final assessment don’t we and then generate a referral. (GP)

Community nurses felt that medication nurses would facilitate better practice, but this was discouraged by the GP.

In an ideal world I think every [RDNS site] ... should have someone that has a medication ... have a medication nurse. So someone who specifically looks at medications and I know it's worked fairly effectively. (CN)

I think looking for whether someone’s complying with the medication and whether they’re taking it is a separate matter, but looking at relationships between different medications and side effects and all that sort of stuff requires a more detailed knowledge of pharmacology than I think is normally there. (GP)

Assessment

As identified in chapter 3 (Something Changes), changing environments as well as changing functional and cognitive abilities may lead to increased medicines support by a family member. The concerns for the individual’s medicine safety either from the family or the GP appears to be the trigger whereby health professionals will need to assess the extent to which there is a problem. Aside from the Home Medicines Review (HMR) and the experiences of using this program, none of the three health professional groups were able to identify a validated and structured assessment process that was used with success in the community environment.

But there’s no actual chart that says can the patient identify the tablet? Can the patient open the packet? Can the patient — there's nothing. You've got to come up with your own ideas as to what you think the problems are going to be. (CN)

But it seems that the hardest one to solve is the people who you haven’t made a formal assessment of them being incapable; you think they’re okay, you think they understand it, but then when someone goes into the house they find stockpiles of drugs and clearly they

\(^4\) The title, practice nurse, refers to a qualified nurse employed by a GP within a GP partnership (Hampson, 2002)
haven’t been taking it for a period of time and nobody’s known about that and you can’t track back to find out where the problem is with that. (GP)

What assessment involves
Health professional participants offered a range of approaches to determine the person’s medicines behaviours. The ability of the individual was normally measured through question and correct answers. This included naming the medicine, correctly describing what it was for, knowing when the medicine should be taken and how, knowing when not to take the medicine, who else is helping.

My screening question is how many doses do you forget? (GP)

When you ask, most people forget them, how often do you forget them? Once a month, you’re going okay. (GP)

Usually if it’s more than once a week I’m putting them in the unintentional forgetting high-risk group. (GP)

Who is looking after their medications for them? Is it them or is it a carer? (Pharm)

So I want to know that they can actually read the label and either say that it’s daily or they can read from the label So that’s my way of saying they know the name of the pill. (CN)

The need to observe the person’s ability to handle the medicine packaging, select and take the correct tablet as prescribed was strongly voiced by the nurse:

So finding out what their abilities are as a base line. (CN)

Can you open the packet? Let’s watch you — those dexterity things. (CN)

Medicine-taking history
Judgments regarding the person’s ability often arose from extended conversations with the person directly, through a family member or through discussion between health professionals:

It might just be a little comment ... the pharmacy assistant may mention it to the pharmacist who then decides to explore it further. (Pharm)

If they’re talking to the practice nurse before they go into the doctor ... It’s the practice nurse who hears the carer saying, you know, she doesn’t take her medications. (Pharm)

Sometime there’s information from family members that might be present, as to what’s been trialled before, and what has worked well and what has failed. (CN)

I think that somehow that this area is really stumbled upon by a combination of the pharmacist and the GP usually talking together ... and if there isn’t a family member that is actually supervising each dose that the patient’s supposed to take, then the system breaks down. Usually at that point the GP finally becomes aware that the patient is not able to remember to take something. (GP)
The Home Medicines Review

The HMR provides a comprehensive review of a person’s medicines regimen in a home visit by a pharmacist in collaboration with their GP. The assessment findings support the development of an agreed management plan. The HMR was deemed to be of benefit due to its ability to identify self initiated medicines and the person’s self management practices at home.

_HMRs are really good because we drag all this information out._ (Pharm)

_The value I find is often finding out what the patient is taking that you didn’t know they were taking._ (GP)

_I would hope that if we had a Home Medicines Review before we went in, a lot of that would be discovered._ (CN)

Yet there was recognition that the program was under-utilised, largely due to the processes and time required by the GP to initiate the process.

_I think that it probably is an underutilised resource._ (GP)

_I just really found that that medication review, it was good to know that that could be done and I don’t think that’s a service that a lot of people know about._ (Carer PWD 6)

_Well HMRs need to go through the GP. So unless there’s some restructuring of the system ... the GP has to be the one to set the thing going._ (Pharm)

_I should do more referrals for HMRs, but my block is just sitting down and having the time to generate the referral because you’ve got to do sometimes a bit of sleuthing to get the medication list right that you think they should be on and then of course the pharmacist also wants their latest renal function at least and any other tests that you’ve done._ (GP)

The reluctance of GPs to use HMRs may be related to their negative experiences with them.

_I have had patients I’ve referred for home medication reviews and we have changed things according to the home medication reviews ... within a couple of months we’ve gone straight back to where we were because we actually ended up with problems._ (GP)

_But equally they could also see from our point of view, as a nursing organisation, the benefits of actually doing one of these._ (CN)

Is the underlying problem of the HMR in its lack of comprehensiveness?

_They [HMRs] don’t look at the person's ability to comply, to get their prescriptions. They don’t look at the whole picture, they just look at the medications._ (CN)
Barriers to Team Work

It was not only the barriers that surround the HMR that impact on the health professional’s ability to complete a comprehensive medicine assessment. The environment in which the health professional needed to work within also caused restrictions. The nature of clinic and shop based consultations raised another barrier to the assessment, as GPs and pharmacists were not always able to recognise when people were experiencing difficulties in safely managing their own medicine. This was further compounded by time restrictions. It was apparent that the range of assessment data on the individual’s medicine taking behaviour was collected across all three health professional groups. It was also evident that there were many barriers to collating and acting on this information in a manner that would support the person’s continued medicine management. As these participants aptly identify, it is important for information to be shared across the medication team, particularly for the GP, as they need to base their clinical decisions on this data for the most appropriate prescribing and management:

I guess on the idea of a team, you share all the information you have; you always share information. (Carer PWD 3)

But I’ve found that anyway most doctors need feedback on what is happening ... They won’t know unless they get some feedback and most patients don’t know what they don’t know and they don’t know what to ask for. (Carer PWD 2).

It’s very frustrating for the GPs when that [medication changes] happen and they don’t know what’s happening. So it’s a link that still needs to be closed. (Pharm)

Silos

Working in silos arose from the perception that health professionals appeared to work independently of each other, limiting the capacity for effective communication and forming collaborative relationships.

There have been occasions where the group has come to a decision; RDNS has come to a different decision and there’s been a lot of friction. (Carer PWD 3)

I think there needs to be more work on integrating community based services. (GP)

I’m not sure how much interaction occurs in the case where you already have a patient who is being seen by a RDNS and the practice nurse in the context of those home visits. (GP)

Communication

Communication was a key component to establishing collaborative teamwork and safe medicine practices at a systems level. All parties involved in supporting medicines management of older person or person with dementia in the community were able to identify the communication gaps. For the GP, the problem existed on several levels, receiving and collating information from other prescribers and the need for community nurse’s to inform them of the people most at risk of medicine error.

Is there good communication between all the providers? The GPs would say no. (Pharm)

So when the nurse is visiting, even though there may have been a referral from a particular doctor ... there isn’t a uniform means of communicating what is actually being consumed from the plethora of sources of prescription. (GP)

Contacting the specialists is very problematic. Many of the specialists don’t have computerised medical records; they’re still using cards. (GP)
So I think it would be good if there were I guess a more structured communication channel between the GP and the RDNS. (GP)

For the pharmacist, it was the frustration of entering a person’s home with the intent to complete the HMR to find the tablets were locked away by the community nurse service. For the community nurse it was the lack of consistency in the information flow between the GP, pharmacist and themselves when prescriptions were altered, and for the family carer it was also the frustration of the health professional group’s inability to communicate with each other, seeing themselves as the only constant.

Yeah, it would be good if we could get some more communication between RDNS and us, because sometimes we don’t know that a person is an RDNS client until we get there and say, where’s your medicine, and they bring out a little red tool box with a lock on it. (Pharm)

The GP will 99 per cent of the time, liaise with the chemist, but won’t fax us anything. We don’t receive a med authority so we have to chase that up. (CN)

In Mum’s situation, with all the groups, I’m the only one who talks to every single one in the group. (Carer PWD 3)

Communication with CALD clients

An additional confounder to communication was identified when working with people from culturally and linguistically diverse (CALD) backgrounds. Ideally, the pharmacists would like to work with interpreting services but as these services have a cost component they have to find alternative means to communicate. Conversely the community nurse had access to interpreter services but found that managing the time associated with an initial assessment visit when using an interpreter was an issue. Of particular concern was the lack of access to translated medicine information sheets to assist with information giving.

Interpreters by far are the best way to help the CALD clients ... but there’s a lack of funding. (Pharm)

Family members are not ideal, and we’ve also had to resort to pharmacy assistants going along to interpret ... it can be a problem. (Pharm).

There's just not enough time with an interpreter there as well ... That first visit is so important for expectations and education. (CN)

Can they read English? ... The information might be there but they can’t access it. (CN)

Relationships between team members

Whilst the systems health professionals work within result in blockages to effective assessment and communication, there were also factors within the working relationships between groups that either hindered or supported collaborative working. The family carer was able to describe good working relationships with their GP and pharmacist, however the same could not be replicated between the community nurse, GP, and specialist. Frustrations, particularly from the community nurse, were heard due to the variable practices in relation to communication and enacting the medicine changes recommended by the specialist.

[The relationship with the GP is] very important really. Because he's the one who decides what is necessary and what isn't necessary. (Carer OP 6)

It has been absolutely vital and extraordinary helpful to have a really good relationship with our new GP. (Carer PWD 2)
It was really difficult to get the doctor to speak directly to the specialist and vice versa. We were kind of the go-between, when it wasn’t necessary. (CN)

The understanding by the wider medication team of the degree to which all medicine and medical related decisions are managed by the GP may well be lacking, but the frustration expressed by this GP demonstrates the implications:

I just think there is a stupid expectation that GP has cover all of everything. (GP)

There was willingness amongst the GPs to consider ways to distribute different medicine management responsibilities.

I think if we could ease the burden, if you like, on the prescribing GP and leave them to assess the patient ... and prescribe optimally ... If we get that right and then have another mechanism, if it is not formally developed yet, to then customise if you like how does the person get the best medication profile? That may mean that somebody responsible for that step then needs to renegotiate with the prescribing practitioner or practitioners because remember there is multiple at times. (GP)

Developing Collaborative Relationships

The sharing of expertise and responsibility for decision making by all members of the medication team underpins a collaborative approach to medicines management. It was anticipated that improvement of assessment processes and communication systems across medication team members would promote this.

Improving assessment

The HMR provides a mechanism to promote collaborative medicine assessments and onward safe management of medicines. As identified earlier in this chapter, there were several barriers to the current use of the program in the community setting. Equally, there remains a lot of support to promote the use of the HMR in the future. Pharmacists would like to see the HMR as part of hospital discharge planning:

If the [HMR] could start with RDNS or ... the discharge planning that occurs in the hospital, part of the discharge planning process. (Pharm)

We’ve often thought a post-discharge medication review — I mean it should be mandatory really. (Pharm)

Whereas community nurses and practice nurses could help to promote the use of the HMR, the practice nurse could promote the program at GP clinic level and through a specialised community nurse to improve liaison between the members of the medication team. This was echoed and extended by the pharmacists who value the monitoring role that community nurses bring to the table:

Well she [the practice nurse] was the one through who I found out I could have this medication review. I think a lot of them [specialists] don’t know that this is a service that is available. (Carer PWD 6)

[A Clinical Nurse Consultant for] medication would be a very good liaison person for those HMRs, wouldn’t it? Like to discuss with pharmacists what that client's particular shortcomings or problems are, to look at recommendations, to really improve the outcomes. (CN)

Nurse practitioner I think we'd probably need to still develop them a little bit more so that GPs can understand their value. (CN)

Even if the doctor doesn’t act on your recommendation in your [HMR] report, the district nurse can see the issue you’ve identified, and they’re in a position to monitor that because
they’re seeing the person on a regular basis. So it would be valuable even if the recommendation wasn’t taken up by the GP. (Pharm)

**Improving communication**

Whilst collaboration was a much sought after goal, it did not feel achievable in the current climate:

> We’ve just got to bring us all together. I don’t know if that’s going to happen. (Pharm)

Suggestions were put forward on how communication issues may be overcome:

> I think the pharmacists and the District Nursing Service need to engage with the practice, in other words become part of the practice team. In that sense, the district nurse or the pharmacist might be a member of a number of teams but I think if you’re not rubbing shoulders with the practice then you’re always on the outside of the team. (GP)

> People are more accessible, people receive calls from a member of their own team, in inverted commas, versus taking an interruption from someone that you’ve never met that happens to identify him or herself as interested in the person’s medication. (GP)

Strategies were proposed that medication review processes should be inclusive of the other health professionals:

> So you would need to supply documentary evidence ... There would actually be some formal steps in that so you’re bringing in other professionals into the review process. (GP)

> Could be part of a care plan for something to have an annual review of their medication which wouldn’t be undertaken by the doctor; it would be undertaken by the pharmacist. (GP)

The importance of the multidisciplinary team was raised and case conferencing was put forward as a viable option.

> I suppose from my point of view, it would also be helpful in the whole multi-disciplinary thing, medications have often got pushed a long way back. (GP)

> I suppose the only other way is with case conferencing happening more often. (GP)

> There are often discharge case conferences with family members. (GP)

Although, some barriers to this include the remuneration for participating and the logistics of arranging one, even in a teleconference format.

> Whilst in theory there is an ability via Medicare to have case conferencing, it isn’t well subscribed to because it’s relatively poorly paid. (GP)

> But whether there was a teleconference of some of those people, the discharging pharmacist, doctor, GP and RDNS and case manager if there is one, perhaps might be a way. But the logistics of that would be a nightmare. (GP)

A systemic approach to improve communication was mooted with evidence that the older person or family carer is the main stakeholder in the medication team, encouraging communication between doctors and across all other stakeholders:

> Whoever is the most constant should be the one getting the information. (Care PWD 3)
I’ve always insisted that my three doctors communicate with each other. (OP 3)

I have asked the GP to send the neurologist report if there’s a medication change and things like that. (Carer PWD 7)

Most accredited pharmacists would want to know before they walked in, that RDNS were involved, and if they’d had, you know, email or phone contact with that RDNS person before they walked in the house. (Pharm)

Strategies to achieve effective communication were put forward and included the use of the internet and communication books:

For me, the ideal situation would be that Mum’s information was on the internet; everybody concerned, including myself, could log in and instead of having the written history. (Carer PWD 3)

We had a communication book as well. So if anybody noticed something we used to write that in the book. (Carer PWD 8)

Communication between the family carer, the health professional and substitute carers

Issues surrounding effective communication were not isolated to the interactions between health professionals. A majority of the family carer participants also experienced anxieties about the communication of the medicine management structures in place for the person they were providing support to. Yet, in contrast to the health professionals, these participants were able to put systems in place to cover the eventuality that they were not in a position to communicate these themselves. Two strategies were described, the backup plan and the medicine list.

Backup plan

The backup plan was largely instigated by concerns either held by the family carer or another family member regarding how to maintain continuity of medicine care for the older person or person with dementia if the carer themselves become indisposed.

I thought I’d better draw up a care plan in case for any reason I’ve got to head off. (Carer OP 3)

Because she [my daughter] said to me one day, before I went in the hospital, she said, I wouldn’t have a clue Mum how to fill these [tablet boxes] up for you. (Carer PWD 1)

Different mechanisms were put in place depending on the family carers support network, for some it was handing the information to another family member, using the GP as backup or maintaining an extensive care folder.

My daughter [is my backup plan] I’ve shown her where the shoe box [of medicines] is. (Carer PWD 2)

I will just have a different sort of folder there which guides people through medications and whatever else is needed and I’m working towards that at the moment. I haven’t got that fully documented. Like an emergency folder, a care folder. (Carer PWD 2)
Carrying an up to date medicine list was also popular for all participants particularly in the event of an emergency to communicate the medicine regime to paramedics, hospital staff and other family members.

*It's just if you had a medical emergency ... you can just take that medication sheet with you.* (Carer PWD 6)

*If I became ill and I couldn't communicate with any medical people, my daughter knows that's there and she would pull that out [list of medications] and she'll give it to them.* (OP 2)

*I suppose it [the medication list] would be beneficial to somebody who doesn't actually know what we take.* (Carer PWD 5)

*We've got one of those medication list things on a board in the front room.* (Carer PWD 5)

The ‘lists’ were described in many different formats, hospital discharge summaries, paper lists generated by the GP, on the mobile phone, a memory stick:

*Well I know when they come home from hospital with those summaries ... I just love the way they're set out, action and when you should be taking this tablet ... It's easy for the client to look at ... I just think that the doctors should have a computer program where they prescribe that that comes out with them. That could just reduce confusion, would help us in our teaching.* (CN)

*Now, I've also put all that [medication information] and mine on my mobile phone in a notes file.* (Carer PWD 2)

*Especially if you have a lot of medication and you put it on this memory stick and then it slips into like a bank card sort of card.* (Carer PWD 5)

*He [the doctor] always will write up, prints it off, it’s all on his computer. I think that’s an excellent thing.* (Carer PWD 6)

**Summary**

Effective medicines management requires collaborative teamwork amongst the members of the medication team; it was perceived by older people, people with dementia and family carers that teamwork was being facilitated. Health professional participants were able to describe each other’s roles and responsibilities to support safe management of medicines and there was an emerging role for the practice nurse within the medication team. Community nurses had expressed a desire for access to nurses with extended knowledge in pharmacology to support practice, a similar model to those in the Hospital Admissions Risk Program. However this idea was not supported by GPs, suggesting that pharmacists could be better utilised for this.

Exploration of health professionals’ assessment practices revealed that apart from the HMR, there were no validated or systematic assessment processes in use to gather information. It emerged that across the three professional groups a comprehensive analysis of an older person or person with dementia’s medicines management ability was gathered, but because of poor relationships and inadequate communication practices the sharing of this information was limited. It was proposed by the health professional participants that these limitations could be overcome by improving the utilisation of the HMR, by using the GP practice as the central point to all professionals to improve relationships and multidisciplinary working, and the use of case conferencing to improve communication.
The factors identified in the study that influence the co-ordination and collaboration of care related to medication management have the following implications for the assessment tool:

<table>
<thead>
<tr>
<th>Medication Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Identify who is involved in medicine management (ascertain the team members)</td>
</tr>
<tr>
<td>- Explore the role and responsibilities of each member and check if roles are agreed and understood</td>
</tr>
<tr>
<td>- Explore if communication between the medication team has broken down</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Ascertained if medicines are taken as prescribed</td>
</tr>
<tr>
<td>- Explore if any questions or concerns exist about medicines</td>
</tr>
<tr>
<td>- Find out if doses of medicines are forgotten</td>
</tr>
<tr>
<td>- Ascertained how often a dose of medicine is missed or adjusted to suit individual needs</td>
</tr>
<tr>
<td>- Identify when a medication review was last conducted</td>
</tr>
</tbody>
</table>
7. Discussion

The responses of participants identified concepts that should be included when screening is undertaken to assess the safe self management of medicines. The discussion points used to guide the assessment tool development included:

1. Person-centred medicines management and the Active Service Model
2. Identification of strengths and weaknesses and personal resources for medicine management.

**Person-Centred Medicines Management and the Active Service Model**

Stewart et al., (1995, as cited in Mead and Bower, 2000) used definitions and concepts to conceptualise patient centred care that are still relevant today and specifically pertinent in relation to medicines management. Their comprehensive description of patient centredness described six interconnecting components:

1. exploring both the disease and illness experience
2. understanding the whole person
3. finding common ground regarding the whole person
4. incorporating prevention and health promotion
5. enhancing the doctor-patient relationship
6. ‘being realistic’ about personal limitations.

(Stewart et al., 1995, as cited in Mead & Bower, 2000, p 1087)

This description provides a sound basis for patient centred medicines management from the doctor’s perspective. This was further complemented by Mead and Bower’s (2000) conceptual framework of patient-centredness with five dimensions based on the relationship between the health professional and the individual:

1. **Biopsychosocial perspective** which looks beyond the presenting illness or disease to explore the psychological and social factors that may impact on the person’s medicines-taking beliefs and behaviours.
2. **The ‘patient-as-person’** understands the meaning and experience of illness for the person in the context of their personality, life history, personal and cultural beliefs and values.
3. **Sharing power and responsibility** promotes a partnership approach between the health professional and the individual that is based on mutual respect. It requires the provision of information at the level indicated by the individual to enable the person to make shared decisions about their health care.
4. **The therapeutic alliance** not only refers to the emotional intelligence skills of the doctor but also to the elements of the relationship between the doctor and the individual that facilitate shared decision making for health care, identified and agreed goals of care as well as the relationship itself.
5. **The ‘doctor-as-person’** describes the influence of the doctor within the doctor-patient relationship, such as their attitudes, values, personality and their emotional responses.

(Mead & Bower, 2000)
Where Mead and Bower talk about the role of the doctor in the therapeutic alliance, we would like to include all members of the medication team, similarly with ‘doctor-as-person’ we advocate that the influences of all parties within the relationship should be considered. That said, the definition provided by Mead and Bower (2000) supports our findings. Participants strongly advocated the need to understand the person in the context of their values, beliefs, and motivation to take medicines and the need to be inclusive of all participants in the decision making processes. Health care professionals who were willing to establish working practices that support cohesive team work and shared information were valued. This necessitates understanding aspects that support the individuals desired level of self determination, good relationships, supporting independence through an individualised approach and effective communication. These factors do not occur singularly and cannot be approached in a linear fashion. For this reason it is proposed that the medicines assessment be conducted in a conversational style within the context of an existing partnership between the person and the health professional.

Person centred components correspond with the principles of the Active Service Model (ASM), which underpins service provision from all Home and Community Care (HACC) providers in Victoria. This approach aims to recognise the desire of people to remain autonomous and their potential to improve their function and wellbeing. This is also congruent with the Quality use of Medicines (QUM) guiding principles (Australian Pharmaceutical Advisory Council, 2006). Assessments utilising this framework should consider the strengths and capacities of an individual, and care should be driven by the person’s goals (State Government of Victoria, 2008). Such an approach requires a collaborative relationship between the person and their service provider, and also strong partnerships between support agencies.

An outcome of the interviews and focus groups identified issues concerned with non adherence and non compliance. According to the World Health Organization (WHO) adherence is defined as “the extent to which a patient behaviour corresponds with recommendations from a health care provider” (World Health Organization, 2003, p. 136). However, adherence could be viewed from a different perspective. Nunes et al. (2009) postulate that non-adherence to medicines should not be seen as a shortcoming of the patient, but as a failing of the prescriber to enter into shared decision making with an informed patient and identify the needs associated with self administration. Barriers to achieving this partnership are the commonly held beliefs by health professionals that they are time poor or the clinical circumstances and patient characteristics are not appropriate for shared decision making (Gravel, Legare, & Graham, 2006). By changing the perspective, it is possible to work towards person centred medicines management from a team approach. In light of this, the language of assessment was directed towards empowerment.

The need for a cohesive team approach was supported by the results of this study and several suggestions were provided as to how this could be undertaken. These included improved multidisciplinary working practices and use of existing processes such the Home Medicines Review and case conferencing. It is anticipated that communication and relationships will be improved through these mechanisms. Within the assessment tool this has been addressed. Questions are asked about the team approach, membership, and the role of each member; the assessment also provides a mechanism to identify when information should be disseminated and how to support it.
Agency (choice, autonomy and self determination)

Choices and the right to make decisions regarding treatment options require information upon which that decision can be based. The drive to ensure medicines are taken safely and correctly may cause the health professional to overlook the principle that people have the right to decide to decline a treatment or to cease taking a medicine (Nunes et al., 2009). Assumptions about the person’s preferences of treatment should be avoided (Nunes et al., 2009). We found quite disparate stances from the older people and people with dementia participants on the wish to receive information and be involved in decisions about accepting medicines. Some were happy to take the medicines based on their trust and faith in their GP’s clinical judgement or because of respect that was inherent of these participants’ generation. This finding was similar to that found by Bastiaens, Van Royen, Rotar Pavlic, Raposo, and Baker (2007) where the GP was described as the authority and expert. Others spoke of using verbal or non verbal strategies to indicate to their GP that they were unhappy with the suggested prescription; the importance of facilitating and observing for the expression of these preferences was discussed by the GP participants, and is supported in the literature (Nunes et al., 2009). This was taken into consideration in the design of the tool as the philosophies of choice, autonomy and self determination underpin what we are trying to achieve.

Relationships

The quality of the relationship between the GP and the older person is an important feature that supports medicine taking behaviours (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008; Heneghan, Glasziou, & Perera, 2006a). Our study found older people and people with dementia invested much time in building a relationship with their GP and pharmacist. Some important characteristics of this relationship were trust and confidence, showing an interest, being a friend and continuity. These findings were similar to Bastiaens et al., who stated:

Features of such a relationship include a supportive, engaged GP whom the patient can trust and who knows his patient and provided a tailored approach. Such a caring relationship is regarded a prerequisite for involvement (Bastiaens et al., 2007, p. 36).

Health professionals that understand the importance of the characteristics of a relationship valued by the older person, person with dementia and family carers can capitalise on it to support medicine taking behaviours. In our study, it was found that continuity was important, with the person’s preference to see the same GP at each consultation, as this was part of the building and sustaining of this relationship. There was a misperception by health professionals that consumers of medicines tended to access multiple doctors and pharmacies. Whilst our older people or people with dementia participants are not necessarily representative of the broader population, not one of them indicated that they did this. Rather, these participants expressed frustration at not always being able to book a consultation with the GP of choice within the practice. They spoke of their willingness to see other doctors as long as they felt their medicines issues were well communicated to the other members of the medical team. These issues will be explored through the assessment tool.
Communication

An Australian study completed by Bhasale et al. in 1998 (Bhasale, Miller, Reid, & Britt, 1998) sought to appraise why potential and actual incidents of medicines related harm to general practice patients occurred. It was established that poor communication between the health professional and the individual and likewise between health professionals topped the most frequent contributing factors. The QUM guiding principles identify that communication and coordination amongst the medication team is essential for the safe use of medicines (Australian Pharmaceutical Advisory Council, 2006). Over a decade later our study participants report frustrations regarding communication gaps between members of the medication team and the potential to affect safe medicines practices. As with Bhasale et al. (1998) and Nunes et al. (2009), we found that there were still problems with receiving clinical information from other prescribers and hospitals in a timely manner. Other incidents included new medication team members failing to advise the existing team of their involvement and the failure to communicate medicine changes across members of the team, particularly where the health professional may be responsible for safe administration of that drug. These issues cannot be resolved through the assessment tool; rather, changes in policy and the introduction of electronic information strategies and the partnerships within the medication team.

The lack of English skills of the person taking the medicines was an element that affected communication between the individual and health professional (Bhasale et al., 1998). The specific issues raised by our study participants were, for some, lack of access to interpreters and for others it was lack of access to translated medicines information sheets. This supports the need to identify the person’s language needs for medicine related information and processes.

Our findings discovered a gap within the person centred framework. It was evident that there comes a critical point where the family carer should be considered as part of the care dyad. This usually occurs when the journey of the older person and person with dementia requires the presence of another person, usually a family member, to step in and support their deteriorating ability to self manage medicines. International data has found that 58% of medication administration by older adults occurs in partnership with another: 42% by daughters, 26% by spouse, 8% by sons, 4% mothers or sisters and 20% others (Fleming, Pulliam, Perfetto, Hanlon, & Bowling, 1993; Thwaites, 1999). The support and assistance from family and friends promotes self esteem, reduces the stress associated with ill health, reduces depression and behaviours associated with being sick, as well as giving practical assistance (DiMatteo, 2004; Schumaker & Hill, 1991; Wallston, Alagna, & DeVellis, 1983).

The family carer’s presence, role and responsibility within the medication team needs to be clearly acknowledged by the other members with provision of support and information to enable them to undertake this role. The development of relationships and communication strategies need to be inclusive of this marginalised medication team member and, as such, provides the rationale for conducting the medicines assessment with any identified family carer present to verify their role and needs to maintain it.
Identification of Strengths and Weaknesses and Personal Resources for Medicine Management

This study found that older people, people with dementia and family carers develop strategies to self manage based on their self perceived level of physical and cognitive ability. These strategies were drawn from the resources available to them and were highly individualised and motivated by their goals of medicines management. When health professionals are applying an Active Service Model and strengths based approach to assessment there is a need to establish strategies that have previously sustained self management as well as identify and remove the current barriers to independence, thereby facilitating independence for longer.

The WHO describe three factors that support behaviour change and adherence to medicines: motivation, information, and self efficacy/behavioural skills (WHO, 2003). Our study found that the older people and people with dementia participants described these factors as being components that enabled them to achieve self management of medicines. Given the correlation to this theory the findings will be presented in the same format.

Motivations

A person’s motivation to adhere to a prescribed treatment is influenced by their beliefs regarding their medical condition, the value they place on following the treatment regime, and their degree of confidence in being able to follow it (Vermiere, Hearnshaw, Van Royen, & Denekens, 2001). There is a need to offer the individual the opportunity to voice any concerns they may have about the treatment (Nunes et al., 2009).

Our findings identified that the motivation to take medicines was prompted by two key factors: the older person’s goal to take their medicines safely and the belief that they were keeping them alive. These motivating factors were strong enough to override the person’s values and beliefs. So even where the older person dislikes taking medicines or believed they were poison, they would still take these medicines and find ways to do so in an effective and continuing fashion. However, participants would find ways to reconcile acceptance of the medicine with their beliefs, for example by expressing a preference to take a medicine that was derived from a natural source or one that provides a direct benefit of symptom relief. Offering the individual the option to consider non-pharmacological options was supported by Nunes et al. (2009) and has been incorporated as an assessment item. Given the concept of motivation appeared to be a driving factor for the decision to take medicines, this is addressed in some depth in the assessment.

Incentives

For the purposes of this study, incentives were described as the act by another person that will provide the motivation of the individual to take medicines. Study participants identified incentives that were secondary but important factors that affect motivation: GP prescribing behaviours (particularly where there was little perceived benefit of treatment), fear or experience of side effects, and familiarity of medicine names and appearance. These are areas that have been described individually in the medicines management literature, but have not been viewed as a collective to provide an underlying component of motivation. We believe the importance of these incentives can be identified as a new area of consideration. The assessment tool explores:

- Expectations of treatment outcomes
- The fear and experience of side effects
- Familiarity of medicine names and appearance
- Medicines information.
There is an increasing understanding of the effect that health literacy has on the person’s ability to read, understand and act on health information (WHO, 1998). A study by Griffiths, Johnson, Piper, and Langdon (2004) found: 25% of people were unable to name, describe and identify the administration times of their medication; 33% had errors in understanding the functions of their medications; and 73% were unaware of the reason for taking the medication.

In our study there was an expectation held by health professionals that older people should be knowledgeable of their medicines, understand what they were for and how they should be taken. Their assessment was targeted to determine if the older person achieved this benchmark. But this study also identified that the older person participants had different levels of information requirements. Some were passive, happy to trust their GP’s professional judgement, whilst the majority actively sought this information. This finding is supported by a European study by Bastiaens et al., (2007) where it was found that the older person’s involvement in their own health care should be viewed as a continuum, with passivity and autonomy in health care decision making as polar opposites and information seeking lying on a scale between the two.

Elderly people differ substantially. Some people would like to be involved, are interested in receiving information, want to know what’s going on, whereas others do not, which makes their involvement difficult. Participants expected the GP to take these preferences into account. (Bastiaens et al., 2007, p. 37)

This suggests that assessment of medicine knowledge is not a requirement; rather it corroborates the need to understand the older person’s attitude towards their information needs so that health professionals can adopt strategies based on the person’s strengths and wishes. This approach has been advocated by Nunes et al. (2009) identifying that information should be in a structured or interactive format, tailored to the individual’s ability and available in different mediums such as websites, pictorial or graphic and tailored to the individual’s ability. When written and coaching interventions are used in combination, this increases knowledge and satisfaction (Nunes et al., 2009). This assessment tool will challenge existing health professional practices that value knowledge, and will explore the person’s attitude to their information needs and act accordingly.

**Self management (self efficacy)**

Self-efficacy is a positive predictor of adherence to medicines in older adults (Arlt et al., 2008). Self-efficacy refers to the belief or confidence that one can successfully perform a specific action required to attain a desired outcome. (Bandura, 1986)

In this study we found that once the older people and people with dementia had established their engagement with treatment they would instigate a process that would enable them to achieve their identified goal, which was usually to safely self manage their medicines. These participants described a range of problem solving strategies they had devised and implemented themselves to help them to remember to take their medicines. These included linking tablet taking to a routine, use of visual cues, aids and adaptations, third party prompts and reminders, memory, and setting up medication organisation systems or dose administrations aids (DAAs).

These strengths based approaches to self management provide guidance to health professionals when they find themselves acting in an advisory capacity to the older person and person with dementia as they experience deterioration in their ability to self manage. These approaches are supported by literature where it is recommended that interventions based on behavioural strategies were favoured over cognitive strategies (Conn et al., 2009). People who decide not to take their medicines are more likely to benefit from educational strategies, ideally in the written form (Conn et al., 2009). Those who experience barriers to their intent to take medication will benefit from behavioural and provider-focussed strategies, such as medication simplification, special packaging and
prompting mechanisms (Conn et al., 2009; George, Elliott, & Stewart, 2008). Prescription management was also perceived to be an important component of self management of medicines by our older people participants, however the literature neglects to address this important component of the medicines management continuum. Whilst not a component of the assessment tool, we anticipate that strategies identified as a result of this study will be made available to staff through a supplementary guidance document.

Medicines simplification

GP prescribing behaviours that support taking of medicines include simplification (Arlt et al., 2008; George et al., 2008; Marek & Antle, 2006) and consistency of the medicine regime (Schlenk, Dunbar-Jacob, Enberg, & Enberg, 2004). These strategies are particularly effective for people with dementia and include minimising the number of prescribed medicines, taking into account the individual’s personal habits when establishing a medicine regime, co-ordinating new prescriptions with the existing medicine schedule and considering alternative preparations for drug delivery such as the use of patches instead of tablets (Arlt et al., 2008).

Our study participants related these factors as an incentive to take medicines and all members of the medication team were keen to employ this approach. Simplification was seen as a strategy that could extend the period that a person could self manage their medicines.

Special packaging

Special packaging in this study was seen as any system that made organisation of medicines easier for the individual. For some, this would involve transfer of tablets from the original packaging to a favoured container. Dosette boxes were preferred by family carers and Webster-paks were popular for people with dementia and where advised by the pharmacist. However DAAs were not a panacea for all, we found that family carers reported that Webster-paks were not so effective for people with multiple deficits such as poor vision, dexterity issues and cognitive impairment. A Cochrane report could not find evidence that use of such systems improved health outcomes, but as a strategy to improve long-term use of medicines, it was found to be effective for some (Heneghan, Glasziou, & Perera, 2006b). Essentially the use of specialist packaging was a highly individualised choice, but people needed to be made aware of their options in this area. This is included in the assessment tool.

Prompting mechanisms

Memory strategies to support adherence include the use of reminders and cues (Schlenk et al., 2004) were also identified within our project. Much of these are covered by the self management and self efficacy strategies. Yet it appears that the management of a prescription is a missing component from the literature. If the medicines management continuum starts from the moment that the person decides to consult their doctor to completion of the prescribed medicine (Thwaites, 1999), then prescription management should feature within this process. Prescription management was a factor for consideration for our participants, particularly the family carers. There was a strong organisational factor involved where the goal was to ensure that tablets were not allowed to run out. Four processes were identified: identifying which tablets need refilling and when, getting a repeat prescription authorised by the GP, filling the prescription at the pharmacy, and collecting it. Many older people, people with dementia and family carer participants devised ways and developed relationships to enable one or all of these processes to be managed. Again it was highly individualised and often dependent on the willingness of the health professional to take part in this process and develop the communication and relationship strategies necessary for its success. Given the unanimous interest in prescription management, these issues are explored in the assessment.
Transient factors

Transient factors in this study were situations that caused the person to experience a change or disruption in their self-management routines and strategies. These included admissions to hospital or respite, introduction or change to the medicines regime, medicines for short term conditions such as antibiotics and analgesia, and medicines with increased risk of adverse drug events if taken incorrectly. In these situations, the risk of error will increase, and people with dementia are particularly susceptible to making errors in medicines administration following a change in their regime (Kralik et al., 2008). Family carers of people with dementia expressed particular concern regarding the loss of ability to follow familiar routines in situations where the medicines task has been removed from them, for example hospital or respite admission. Given the increased potential for error in these situations, it has been addressed as an item in the assessment.

Monitoring

Medicines management does not end with the completion of the assessment. There are multiple reasons for a monitoring role to be instigated when long term medicines are indicated. Over time, it becomes harder for a person to follow the medicine regime (Marek & Antle, 2006) and to use dose administration aids (Thwaites, 1999). Monitoring should identify when people under or over medicate, when they are no longer using inhalers and other medicine dispensing devices appropriately, identify side effects and medicine effectiveness (Marek & Antle, 2006). Due to the pharmacokinetic and pharmacodynamic nature of medicines in the older adult, reviews should take place at least annually and or more frequently in acute or acute on chronic presentations (Bergman-Evans, 2004), or if taking four or more medicines (Shaw, Seal, & Piling, 2002). Reassessment is necessary due to influences that change over time (Arlt et al., 2008), reaffirming the QUM guiding principles, which advocate for a partnership approach and shared responsibility of all members of the medication team (Australian Pharmaceutical Advisory Council, 2005). The assessment tool will reflect the need for this monitoring component.

Contribution to knowledge

The outcomes of this study have contributed to knowledge in the following ways:

- A person-centred and strengths-based approach to assessment is achievable.
- The family carer needs to be considered as part of the care dyad and given support to enable them to undertake the medicines management role for their relative.
- The support of language needs for non-English speaking people should be facilitated through involvement of interpreters and access to medicines information in language of choice.
- GP prescribing behaviours, the perceived benefit of treatment, avoidance of side effects, and continuity of medicine names and appearance are important incentives that support the person’s motivation to take medicines as prescribed.
- There is a need to understand the older person’s attitudes towards their information needs rather than measure their level of medicines knowledge.
- Prescription management is an important component within the medicines management continuum and requires individualised approaches to enable older people in the community to sustain this activity.
- The medication team need to recognise and undertake a monitoring role as there are many factors that influence the older person’s ability to sustain safe self-management of medicines over time.

Future directions

There is a need for health professionals involved in the medication team to remove the barriers and to enable relationships and communication to flourish. Specifically, there is a
need to change processes and policies regarding the dissemination of assessment outcomes.

The aim of this study was to utilise the findings in the development of an assessment tool. This has been achieved. The tool is in its first draft and requires further research:

- Delphi technique using experts and clinicians to increase face validity of the assessment tool.
- Test the tool for validity and reliability in the clinical setting.
- Evaluate useability with other community care organisations within Australia.

The target health professional group that intend to utilise the assessment tool in practice are community nurses. As mobile computers are used in daily practice there is a need to develop an electronic version of the assessment tool with decision support resources. There will also be a need to integrate person centred and strengths based assessment principles into the accompanying medicine management education program.
8. References


University of Queensland (2004). *Effectiveness and Cost Effectiveness Of Dose Administration Aids (DAAs)*. Queensland: Therapeutics Research Unit.


Appendix 1

Administration Instructions:

It is recommended that the assessment be completed at the time medicines are due to be taken by the client.

Assessment should be conducted in a conversational manner.

The categories listed provide prompts for completing the assessment.

The client and carer columns should be marked to indicate who is responding to the question.

Action column: actions help to attain the client’s goals for self management. Please indicate the agreed actions that have been identified for each category.

Refer to accompanying guide for possible interventions (as identified by research participants and evidence based literature). NB: this is not an exhaustive list.

Review date: provide a date for reviewing progress.
<table>
<thead>
<tr>
<th>Category : Capacity</th>
<th>Client</th>
<th>Carer</th>
<th>Findings</th>
<th>Action</th>
<th>Review date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Show me all the medicines you are currently prescribed</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Show me the medicines you are currently taking (explore - prescribed, natural medicines, over the counter, supplements)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Have you stopped taking any medicines that you were previously happy to take?</td>
<td></td>
<td></td>
<td>No</td>
<td>HMR Check for depression, delirium, cognitive change and other physical and mental health conditions.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Yes (explore reason)</td>
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<td></td>
<td>Document response:</td>
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<td></td>
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<tr>
<td>On a scale of 1 – 5: How confident do you feel in how you manage your medicines?</td>
<td></td>
<td></td>
<td>1 = not at all confident</td>
<td>Check medicines are stored as indicated</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 = not very confident</td>
<td>Discard out of date and discontinued medicines</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 = neither confident or not confident</td>
<td>DAA’s</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 = reasonably confident</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>5 = very confident</td>
<td></td>
<td></td>
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<tr>
<td>Show me how you store and organise your medicines?</td>
<td></td>
<td></td>
<td>Location</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Satisfactory</td>
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<td></td>
<td></td>
<td></td>
<td>Unsatisfactory (describe)</td>
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</tr>
<tr>
<td>Show me how you take your medicines?</td>
<td></td>
<td></td>
<td>Packaging</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Dispensing</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Watch administration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is this working for you?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If response is NO: Is any aspect of this difficult or concerning?</td>
<td></td>
<td></td>
<td>Document response:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is your medicine regiment flexible enough for you?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(explore timing, frequency of doses)</td>
<td></td>
<td></td>
<td>Document response:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do changes in name and/or appearance of your medicines cause you concern?</td>
<td></td>
<td></td>
<td>Describe:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty remembering to take medicines?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Document response:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you tried any DAAs or medication aids to assist with taking your medicines?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Document response:</td>
<td></td>
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</tbody>
</table>

© RDNS Ltd
<table>
<thead>
<tr>
<th>Category : Access</th>
<th>Client</th>
<th>Carer</th>
<th>Findings</th>
<th>Action</th>
<th>Review date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who supports you with your medicines?</td>
<td></td>
<td></td>
<td><strong>Identify supports/people involved and document what they do:</strong> GP (regular or variable) Pharmacist (regular or variable) Specialists Community nurse Case manager/ community carers Neighbour friend Family (carer) Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who takes overall responsibility for co-ordinating medicines from multiple prescribers?</td>
<td></td>
<td></td>
<td>Details:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are these people your provider of choice?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td>Document response:</td>
<td></td>
</tr>
<tr>
<td>Do you have difficulty accessing these supports?</td>
<td></td>
<td></td>
<td>Yes/No</td>
<td>Document response:</td>
<td></td>
</tr>
<tr>
<td>How do you identify which medicines need reordering and when?</td>
<td></td>
<td></td>
<td>Self</td>
<td>Other</td>
<td>Describe:</td>
</tr>
<tr>
<td>How do you get the repeat prescriptions authorised?</td>
<td></td>
<td></td>
<td>Self</td>
<td>Other</td>
<td>Describe:</td>
</tr>
<tr>
<td>How do you fill a prescription?</td>
<td></td>
<td></td>
<td>Self</td>
<td>Other</td>
<td>Describe:</td>
</tr>
<tr>
<td>How do you collect your medicines from the pharmacy?</td>
<td></td>
<td></td>
<td>Self</td>
<td>Other</td>
<td>Describe:</td>
</tr>
<tr>
<td>Is cost a barrier in accessing your medicines?</td>
<td></td>
<td></td>
<td>Describe:</td>
<td>Safety net, Health Care Card Use of Generics or branded medicines</td>
<td></td>
</tr>
<tr>
<td>Are you aware of the benefits that may be available to you in relation to accessing medicines?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Category : Attitudes to Medicines</td>
<td>Client</td>
<td>Carer</td>
<td>Findings</td>
<td>Action</td>
<td>Review date</td>
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<tr>
<td>What motivates you to take your medicines?</td>
<td>Document response:</td>
<td>Educational, Behavioural, emotional supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What makes it difficult for you to take them?</td>
<td>Document response:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>What do you expect from your medicines?</td>
<td>Document response:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are they meeting your expectations?</td>
<td>Yes/No&lt;br&gt;No: describe issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How do they make you feel? <em>(explore side effects and adverse drug reactions)</em></td>
<td>Document response:</td>
<td>HMR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have concerns about the interactions or side effects of your medicines?</td>
<td>Yes/No&lt;br&gt;Document response:</td>
<td>HMR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would you prefer a non pharmacological option to the medicines your doctor prescribes you?</td>
<td>Yes/No&lt;br&gt;Document response:</td>
<td>Facilitate discussion with doctor; discuss non pharmacological options if appropriate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category : Medicines Information</td>
<td>Client</td>
<td>Carer</td>
<td>Findings</td>
<td>Action</td>
<td>Review date</td>
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</tbody>
</table>
| How much knowledge do you like to have about your medicines? |        |       | *Tick all that apply*  
What to take  
When to take it  
Condition it is treating  
Names  
Special instructions  
How it works  
Side effects  
Potential interactions with food and other medicines  
What to do when I miss a dose  
Long term implications of the medicine  
Other: ...........................................  
None of the above |        |       | Education Support |        |             |
| Are you getting the information that you want in the form that you want it? |        |       | Yes/no |        |             |
| Where would you prefer to be getting your information from? |        |       | *Tick all that apply*  
Doctor  
Pharmacist  
Nurse  
Internet  
Mobile phone applications  
Information leaflets  
Other: ........................................... |        |       |             |        |             |
| In what form do you like your information to be presented? |        |       | *Tick all that apply*  
Language specific  
Spoken  
Written  
Large print/ Braille  
Audio/ visual  
Electronic- iPhone, internet |        |       |             |        |             |
### Category: Continuity, complexity and change

<table>
<thead>
<tr>
<th>Client</th>
<th>Carer</th>
<th>Findings</th>
<th>Action</th>
<th>Review date</th>
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</thead>
<tbody>
<tr>
<td>Do you experience frequent medicine changes? <em>(these may result from hospital admissions or specialists visits)</em>&lt;br&gt;What are the issues that arise from this?</td>
<td></td>
<td>Yes/No&lt;br&gt;Describe:</td>
<td>HMR prior to discharge&lt;br&gt;Medicines list&lt;br&gt;Prompt Hospital discharge info to GP</td>
<td></td>
</tr>
<tr>
<td>If you have extended hospital or respite stays how do these affect your ability to resume self management of medicines on return home?</td>
<td></td>
<td>Describe:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Category: Carer

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<tr>
<th>Client</th>
<th>Carer</th>
<th>Findings</th>
<th>Action</th>
<th>Review date</th>
</tr>
</thead>
<tbody>
<tr>
<td>What assistance do you need as a carer to safely manage medicines?</td>
<td></td>
<td>Describe:</td>
<td>Support&lt;br&gt;Telephone help lines <em>(Commonwealth respite and care link centre 1800 059 059)</em>&lt;br&gt;Education&lt;br&gt;Counselling&lt;br&gt;Nurse as monitoring role&lt;br&gt;Complete RDNS carer assessment</td>
<td></td>
</tr>
<tr>
<td>What are your goals for medicines management for your relative?</td>
<td></td>
<td></td>
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</table>

### Client:

<table>
<thead>
<tr>
<th>What are your goals for medicines management?</th>
<th>Review date</th>
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</table>
Appendix 2

Invitation to Participate

Older people and their family members are invited to take part in interviews which will explore their perspectives on how they manage their medications.

The Helen Macpherson Smith Institute of Community Health has been funded by the Estate of the Late Glen W Griffiths to undertake a project to ‘Improve medication management for older people and those with dementia living in the community’.

Project Aims

This research project is being carried out so that the nurses at Royal District Nursing Service can provide the right level of medication support to their clients.

We would like you to tell us about any difficulties you experience or have experienced in managing your medication. We would also like you to provide us with some advice about what strategies help you to overcome any medication related activities.

We also want to hear the views of family members about what type of support that they provide and how health professionals can assist them with this role.

The views of district nurses, general practitioners and pharmacists are also being sought about their current medication management practices.

Ethical approval for this project was given by the RDNS Research Ethics Committee.

Interviews will be conducted in 2010. Ideally these interviews will take place at your home address at a time to suit you.

If you think you are likely to incur any out of pocket expenses as a result of taking part in an interview, please advise the researcher who will be able to assist you to access reimbursement to a maximum value of $50.

If you are interested in taking part in an interview please phone:

Chris While (03) 9536 5232

OR e-mail your details (name, address, and phone number) to: cwhile@rdns.com.au

Once you have registered your interest, Chris will contact you to discuss the project and arrange an interview date, time and venue.

Name

Address

Phone

Mobile

Email

Administration Only

RA0084: Interview

Date

Time

Venue
Appendix 3

Plain Language Statement
(Older People, People Living with Dementia, Family Members)

Date:

Project Title: Medication - Improving Management

Names of people doing this project:

- Susan Koch, Associate Professor, RDNS Helen Macpherson Smith Institute of Community Health
- Christine While, Research Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Fleur Duane, Research Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Georgie Rist, Research Officer, RDNS Helen Macpherson Smith Institute of Community Health

What is the project about?

Royal District Nursing Service (RDNS) provides care to many older people who require help with taking their medication. We want to learn more about how people living in the community maintain their independence with medication management and how RDNS can support this.

What does your participation in the project involve?

You have been invited to take part in this project because your views are important to us. We would like to talk to you about how you manage your medication. If you are a family member we would like to get your observations and experiences of how the person taking medication manages the task and any support that you provide.

One of the research officers will arrange to visit you at home. The interview will be planned for a time that is convenient to you and will take about an hour.

What happens with the information you give us?

The discussion that takes place will be taped so that a record of the interview is kept. The information that you give us will be combined with data collected from other interviews. The results will help us to improve the way in which RDNS provides medication management support to clients in the future. We do not believe that taking part in this project will cause you any discomfort or distress.
We will write a report, publish articles in health journals and talk at conferences about the results of this project. What we find out will not include your name or anything that shows who you are.

All of the project data will be stored securely at the Helen Macpherson Smith Institute of Community Health. It will be kept for a minimum of 5 years after the date of the last publication then destroyed.

Ethical approval for the conduct of this project has been given by the RDNS Human Ethics Research Committee.

**Who decides if you take part in the interview?**

Please read this plain language statement carefully. You may want to talk about your decision to take part with a friend or family member. A list of discussion points has been given to you as well. Once you understand what the project is about and would like to be interviewed, you will be asked to sign a consent form by the research officer.

You are under no obligation to take part in the interview and any decision you make will not affect any current or future relationship with RDNS. If you decide to take part but later change your mind, please notify a member of the project team. Any of your information which has not undergone analysis will be removed.

**If you have any questions about this project, please contact:**

Christine While  
Research Officer,  
RDNS Helen Macpherson Smith Institute of Community Health  
31 Alma Road, St Kilda, 3182  
Tel: 9536 5232

**If you have any complaints about the conduct of this project, please contact:**

Dr Lisa Donohue  
Chair, RDNS Research Ethics Committee  
31 Alma Rd, St Kilda, 3182  
Tel: 9536 5322

Thank you for thinking about taking part in this important project.  
Yours sincerely,

**Christine While**  
Research Officer  
RDNS Helen Macpherson Smith Institute of Community Health
## RA0084 Interview Questions

### Participant Interview

<table>
<thead>
<tr>
<th>Themes</th>
<th>Questions and prompts</th>
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</table>
| **Definition**                              | **What do you think is involved in the management of your medication?**  
**Prompt:** Identify the range of people that you see in relation to your medications and what their role is  
**Does being on medication result in the belief that you are ill? If so, describe this further** | |
| **Barriers to optimal medication management** | **Can you identify any medication tasks that are difficult for you?**  
If **Yes:** Why are they difficult for you?  
**Describe any difficulties that you have experienced in taking your medication**  
**Prompt:** Functional ability (mobility, sensory, dexterity)  
Health status/condition  
Cognitive function/ memory  
Access to medications (getting to the GP or pharmacist, affordability of medications) and aids  
Availability of support  
**What strategies have you found help to overcome this problem (with your eyesight, memory, health, language, mobility etc).**  
**Do you sometimes forget to take your medications?**  
If **Yes:** Describe the circumstances in which this might happen  
**And:** Describe any methods you use to help you remember to take your tablets. | |
| **Safe use of medication**                  | **What packaging and medication administration products cause you difficulty in managing your medication?**  
**Prompt:** If you have a health condition that makes it harder to take your medication please describe why.  
**How confident do you feel about how you manage your medications?**  
**Are there any particular medication characteristics or instructions that cause you difficulty?**  
**Prompt:** Describe what they are (pulse monitoring, not crushing tablets, measuring fluids)  
Have you found any ways of overcoming these difficulties?  
**What do you do with your unused medications?**  
**Have you ever seen a Chinese herbalist? If so what level of information have you given them about your current health status and treatments?**  
**When you think of over the counter medications or Chinese herbs, do you think of these as medications like those the DR prescribes?** | |
## Participant Interview

<table>
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<tr>
<th>Themes</th>
<th>Questions and prompts</th>
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</thead>
</table>
| **Assessment**                 | - Have you ever been asked to demonstrate your ability to take your medications?  
  **Prompt:** By whom and describe what you were asked to do  
- Have you ever been asked to demonstrate your knowledge of your medication?  
  **Prompt:** If so, by whom and describe where it took place and what did they ask you.  
- Does the age or generation of the health professional that is either prescribing or dispensing your medication make any difference to you? If so, describe why. |
| **Supporting choice (adherence)** | - Do you take any self purchased/over the counter medicines, vitamins or any other supplements or complementary medicines?  
  **Prompt:** Would you tell your GP and pharmacist about these?  
- What circumstances would result in a decision to not take your medication as the doctor has prescribed for you  
  **Prompt:** Would there be any reason because of your personal or cultural beliefs? |
| **Interventions**              | - Describe the strategies you use that help you to take your medication.  
  **Prompt:** Ask the participant to describe their medication routine step by step. |
| **Receiving help**             | - Who provides support or advice about your medications and how you take them?  
- When you go to the Dr for an ailment/illness, who makes sure you know about the medications given to you?  
  **prompt:** GP, practice nurse, pharmacist, other person or the web  
  **Prompt:** Is this information easy to understand? Do you find this information useful?  
- When would you make a decision that you were no longer able to manage your own medications?  
  **Prompt:** What sign would indicate you could no longer manager your medications?  
- Describe how you think you would feel if this was to happen.  
- What would you want to see happen if this should ever occur to you? |
## Appendix 5

### Family Member Interview

<table>
<thead>
<tr>
<th>Themes</th>
<th>Questions and prompts</th>
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</table>
| **Definition**                              | - What do you think is involved in managing medication?  
- Identify the range of people that you see in relation to your medications and what their role is                                                                                   |
| **Barriers to optimal medication management** | - Describe any difficulties that the family member you care for experiences, in taking their medication.  
- What is the underlying cause of these difficulties?  
  **Prompt:** Functional ability (mobility, sensory, dexterity)  
  Health status/condition  
  Cognitive function/ memory  
  Access to medications (getting to the GP or pharmacist, affordability of medications), packaging and other medication aids and equipment  
  Availability of support  
- What strategies have you found help to overcome this problem that you have described (with your eye sight, memory, health, mobility, language etc) |
| **Safe use of medication**                  | - What packaging and medication administration products cause you or the person you care for difficulty?  
  **Prompt:** Identify which products are a problem  
- What strategies do you suggest would help overcome the identified problem?                                                                                                       |
| **Supporting choice (adherence)**           | - Describe situations in which you have felt concern about your relative’s ability to manage their medication.  
  **Prompt:** How did you manage this?  
- To your knowledge has any health professional involved with the medications discussed the management of unused medication with you or the person taking the medication?  
- In your experience, have you found any strategies that improve the family member’s ability to self administer their medication without error? |
| **Giving help**                             | - What sort of situations would make you feel you have to take over the medication management of another person,  
  **Prompt:** What were the triggers?  
- What experiences have you had since taking over the management of another person’s medication?  
  **Prompt:** Would you say that these experiences have caused or decreased feelings of stress or burden?                                         |
| **Receiving help**                          | - Who is available to you to provide support or advice about the medications being taken by the family member?  
  **Prompt:** How are your GP and pharmacist helping you? Is there anyone else involved that we haven’t mentioned?  
- What kind of help did they give you?                                                                                                                                         |
## Health Professionals Focus Group

<table>
<thead>
<tr>
<th>Theme</th>
<th>Questions and prompts</th>
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</table>
| **Definition** | • How would you define medication management?  
• How would you describe the tasks of medication management to your client? |
| **HARP** | • For the purposes of this project, please could you briefly describe the remit of the HARP program?  
• Does the HARP program have a specific definition of medication management?  
• Please could you describe your role in HARP in relation to medication assessment?  
• What is it that HARP program offers in relation to medication management that is different from mainstream RDNS medication practices?  
• From your HARP perspective, what are the qualities and knowledge base required to undertake an accurate assessment of a client’s ability to safely self manage their medication? |
| **Barriers to optimal medication management** | • Describe the barriers that you think clients experience in taking Medication.  
**Prompt:** Functional ability (mobility, sensory, dexterity)  
Health status/condition  
Cognitive function: memory; language etc  
Access to medications, aids  
Availability of support  
• How do you identify when a client is experiencing any of these barriers?  
• What strategies have you suggested or recommended to overcome these.  
• What packaging and medication administration products cause difficulty for the client to manage?  
**Prompt:** Identify which products are a problem and why  
• How do you assess when these difficulties are being Experienced  
• What strategies do you suggest would help overcome the identified problem? |
| **Safe use of medication** | • What do you regard as unsafe use of medication?  
**Prompt:** Taking too many tablets, contraindications such as alcohol  
• How do you recognise when they are happening?  
• What would you describe as the common issues in patients who are not able to safely manage their medications?  
• What strategies could be put in place to overcome these issues?  
• *(Question for DNs)* How do you verify that the prescription that you have been asked to administer reflects the actual medication that has been self administered by the client? (e.g. If the client is Px a 20mg dose of a statin, do you check that this is the amount the client has been taking) |
<table>
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<tr>
<th>Theme</th>
<th>Questions and prompts</th>
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</table>
| **HMR**               | • *(Question for GP)* Can I ask if members of the group have used the HMR and if they found them to be instructive or useful in any way?  
• *(Question for DN and GPs)* It has been raised in one of the previous focus groups that there would be a huge advantage of having a HMR conducted prior to the GP referring to RDNS for medication management. What do you think of this?  
• *(Question for GPs)* A comment has been made in previous focus groups that the HMR would be useful for doctors through the provision of information and in the long run save time. What are your thoughts on this? |
| **Assessment**        | • What assessment do you undertake to ascertain medication safety in your client?  
  **Prompt:** Describe any criteria that you follow  
  Describe any Assessment tools that you use (HMR)  
• What steps do you think are required to assess if the client is able to independently and safely take their own medication  
• Describe your role in the assessment of the client’s ability to take their medication.  
• What would alert you to suspect a client is not managing their medications? |
| **Supporting choice (adherence)** | • How do you differentiate between clients that **do not want** to adhere with those **who cannot** adhere to their medication regime?  
• Describe how you consider the clients personal and cultural beliefs and the effect it has on their management of medication.  
• Describe how you take into account the client’s daily routine in the prescription or administration of medications.  
• Describe how you take into account the clients use or preference for over the counter medications as well as Complimentary and alternative medicines.  
• Do you discuss the management of unused medication with the client |
| **The medication team** | • Describe any organisational, health professional or resource issues that in your experience affects the way that medication is managed.  
  **Prompt:** Multiple prescribers (Nurse practitioner, other GPs, hospital, specialists, private sector, Allied health, CAM therapists)  
  Multiple pharmacy use  
  Lack of continuity of nurse provider  
  Lack of translator  
• Describe your relationship with others involved in the medication management process?  
• What medication related information do you receive from other health professionals involved in a client’s care?  
• How is that information transferred across all parties?  
• *(Question for DN)* Can you describe a role for the CNC or Nurse practitioner in medication management? |
<table>
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<tr>
<th>Theme</th>
<th>Questions and prompts</th>
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</thead>
</table>
| **Hospital / Community interface** | • *(Question for DN and GPs)* It has been raised that a post hospital discharge medication review should almost be mandatory. What do you think?  
• *(Question for GPs)* In relation to people being discharged from hospital – can the discharging physician or surgeon request a HMR or does it have to go through the GP?  
• *(Question for GPs)* We are hearing from previous focus groups that communication between the Hospital and the GP about their patients discharge and medication is inadequate. Can you expand on this at all? |
| **Interventions** | • What strategies or resources have you found effective in supporting an older person to independently manage their medication?  
• What is the minimum level of understanding that you expect your patient to have of their medication regime?  
• If the patient doesn’t reach that minimum, what would your next step be?  
• What education do you provide your client about their medications? |
| **Supporting family carers** | • How do you identify when family members or other informal care givers are assisting with a clients medication management?  
• Describe what support you do give or could give to informal care givers who assist another to manage their medications.  
• When would you advocate for a family member (or other legal guardian) to take over the management of another person’s medications, and how would you manage it. |
|  | • What are the opportunities for health professionals in providing patients with optimal medication management support and regular review?  
HARP: If there is anything else that arises as a result of the analysis, would you be available to clarify or respond to queries? |