



Response to the Consultation Paper

The Medication Management in Residential Aged Care Facilities Project

**Carers Australia
July 2011**

About Carers Australia

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition or terminal illness or who are frail aged. Carers Australia's members are the eight state and territory Carers Associations.

Carers Australia's Strategic Plan 2009-2012 has a vision that 'caring is accepted as a shared community responsibility' and a mission 'to lead change and action with and for carers'. We advocate on behalf of Australia's carers to influence policies, programs and services at a national level and we do so in collaboration with Carers Associations.

Carers Australia believes that all carers should have the same rights, choices and opportunities as other Australians. Carers should be able to enjoy optimal health, social and economic wellbeing and to participate in family, social and community life, employment and education.

Acknowledgements

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Introduction

Australia has about 2.6 million carers, people who provide assistance to those who need help on account of disability, chronic illness or old age. Of these, about 770,000 are primary carers, people who provide the majority of informal care.¹ Carers are usually family members but they can also be friends and neighbours. The caring role is a diverse one. It encompasses practical help like domestic work, shopping, transport and administration. Carers help with personal care such as bathing, hygiene, feeding and dressing. Commonly carers are responsible for management of medications. They provide emotional support and often assume an advocacy role on behalf of the care recipient. Carers are usually very close to the person for whom they care and deeply committed to their well-being.² The support and care which carers provide and the relationship they have with care recipients also means that carers, in particular primary carers, would normally have a comprehensive knowledge of the care recipient's medical history and health status. Many carers develop considerable skills in aspects of caring.³ Because of the work they do, the support they provide and the knowledge they have, carers are an invaluable component of Australia's health system and an important partner within that system in the provision of care.

When we think of carers and the role they play, we normally put them in a domestic or household setting.⁴ Yet many carers continue to have a close relationship with the person for whom they have cared should that person move into a residential aged care facility (RACF). The nature of the care and support provided would of course change, for example the RACF staff would normally be expected to take main responsibility for personal care services to a resident. In many cases, however, a friend or family member of a resident provides important continuing care and support. Typically this caring role entails regular visits and other social activities but it also, commonly, extends to emotional support and advocacy. And just as in the situation previously at home, the now 'outside' carer will often have a comprehensive knowledge of the care recipient's medical history and health status. Where a resident chooses to manage their own medication, a carer may continue to be involved in this aspect of care. Even should the responsibility for management of medications be passed to the RACF, a carer will often continue to take an active interest in this aspect of a resident's care.

With this background the remainder of this submission is structured along the lines requested in the consultation paper.

¹ Australian Bureau of Statistics, *4430.0 Disability, Ageing and Carers Australia: Summary of Findings, 2009*, Canberra, Dec 2010.

² House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, April 2009, Canberra, pp43-7.

³ *Ibid.* p88.

⁴ Estimates of numbers of carers contained in ABS 4430.0 include some but probably only a minority of carers of residents of residential aged care facilities.

A. Key Influences on Medication Management in RACFs – Commonwealth Recognition of and Support for Carers

The role of carers and the valuable contribution they make to society was formally recognised by the Australian Parliament last year with the passage of the *Carer Recognition Act 2010*. Included in this legislation is a *Statement for Australia's Carers*. The Statement contains ten key principles (*carer principles*) that establish how carers should be considered and treated by Commonwealth agencies and relevant organisations funded to support carers. Several of the principles incorporated in the legislation are of particular relevance in the context of carers in RACFs:

Principle 6: the relationship between carers and the persons for whom they care should be recognised and respected.

Principle 7: carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Principle 8: carers should be treated with dignity and respect.

Principle 10: support for carers should be timely, responsive, appropriate and accessible.

Under the *Carer Recognition* legislation, a care provider such as a RACF is obliged to take all practical measures to ensure that:

- (a) its officers, employees and agents have an awareness and understanding of the Statement of Australia's carers, and
- (b) it, and its officers, employees and agents, take action to reflect the principles of the Statement in developing, implementing, providing or evaluating care supports.⁵

While the legislation creates an obligation on RACFs this is not a legally enforceable obligation (s10). If the Commonwealth Parliament's objectives in relation to carers are to be fully embraced by RACFs it is likely that other means of encouraging adoption will need to be found.

Under the *Carer Recognition* legislation a public service care agency such as the Department of Health and Ageing is also under obligation.

s8(i) Each public service care agency is to take all practical measures to ensure that it, and its employees and agents, take action to reflect the principles of the Statement for Australia's Carers in developing, implementing providing or evaluating care supports.⁶

DoHA will be accountable to the Parliament for its compliance with the requirements of the legislation and must prepare a report on its compliance for inclusion in its annual report.

⁵ *Carer Recognition Act 2010*, s9.

⁶ s4 of the Act defines a public service care agency as an agency that is responsible for the development, implementation, provision or evaluation of care supports. Care supports are defined as policies, programs or services directed to carers or the persons for whom they care.

Carers Australia believes that the most obvious of practical measures that DoHA could take to ensure its compliance would be to incorporate the relevant carer principles into the Accreditation Standards that RACFs must demonstrate they meet if they are to receive residential care subsidies from DoHA. An individual RACF could then be expected to incorporate the *carer principles* into its operating philosophy and practices as part of its efforts to ensure continuing accreditation.

The *carer principles* are relevant to the breadth of RACF operations. This submission is about one aspect of RACF operations, medication management. The existing version (2002) of *the Guidelines for Medication Management in Residential Aged Care Facilities* (the *Guidelines*) was of course prepared some years before the enactment of the *Carer Recognition* legislation. Carers Australia believes that in revising the *Guidelines* DoHA and its consultants should take into account the *Carer Recognition* legislation. Some specific suggestions are made below but generally the revision should make clear that in medication management, RACFs should accept carers as partners in care, treat carers with respect and dignity and support carers in their caring.

The Carer Recognition legislation (s5) also provides a clear definition of *carer*. To avoid confusion about the meaning of term and to distinguish from paid carers we suggest that this meaning of the term be made clear in the *Guidelines*.⁷

B. Comments on 'Introduction and Preamble'

Our comments relate to section 2.3 of the current *Guidelines* 'Residents' and proprietors' rights and responsibilities'. The rights of residents mentioned in this section are consistent with the *Charter of Residents' Rights and Responsibilities in Aged Care Services*⁸ but a number are more detailed and specific to medication, for example the right to obtain pharmacy services from the pharmacy of their choice. It is important that these more specific rights, not just the Charter rights, are brought to the attention of residents, and prospective residents, and their carers. They should also be included in the proposed 'Plain Language Summary for Consumers and Carers'.

In view of the enactment of the *Carer Recognition* legislation, Carers Australia believes that this section of the *Guidelines* should also refer to carers' rights. These should be based on the principles in the *Statement for Australia's Carers* mentioned above but expressed as they apply in the situation of medication management in RACFs. For example, the carer should

⁷ s5(i) of the Act says

For the purpose of this Act, 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; or
- (b) has a medical condition (including a terminal or chronic illness); or
- (c) has a mental illness; or
- (d) is frail and aged.

⁸ *Aged Care Act 1997*, Schedule 1

have the right, with the consent of the resident, to have their identity and contact details included in the resident's medication chart; to be consulted as part of a review of a resident's medication; and wherever possible to be consulted, and in all cases to be promptly advised, of any change in the resident's medication regime. These rights should also be included in the proposed 'Plain Language Summary'. As is already the case for residents, it may also be appropriate to include reference to carer responsibilities (as is currently included in Rec 13 about complementary medicines).

C. Comments on Existing Recommendations in the *Guidelines*

The principles of treating carers as partners in care, of respecting the relationship between resident and carer and of appropriate treatment of carers by RACFs should be incorporated in the *Guidelines*. In particular:

Recommendation 2: where consent has been given by the resident, the identification and contact details of carer should be included in the resident's medication chart. The chart should also make clear the role played by the carer, for example whether they are also the 'person responsible' in matters of health treatment.

Recommendations 3,6,7,8 and 9: when a change to a resident's medication regime is under consideration, wherever possible, and where there is prior consent given by the resident (for example as stated in the resident's medication chart) the resident's carer should be consulted. In all cases the carer should be advised of a change in a resident's medication regime.

D. n/a

E. Possible New Topics

We suggest that consideration be given to including within the revised *Guidelines* information about two subjects not covered in the existing *Guidelines*.

Management of Pain in RACFs

It is now well understood that unrecognised and untreated pain is common amongst residents of RACFs with studies indicating that between 28% and 86% of residents experience pain on a regular basis. Much pain goes undiagnosed in large part because many residents have impaired cognitive and communicative abilities. According to a 2005 report, 40% of Australian nursing home residents were totally unable to report pain due to a major cognitive or communicative disability. The same report indicated that many elderly people without cognitive or communicative impairment do not report their pain because, for

example, they think it an inevitable part of ageing; they fear pain may auger a worsening of disease; or because they do not want to be seen as complainers.⁹

The management of pain in RACFs is obviously more than a medication issue. For example, it involves issues of pain identification and assessment and of non-pharmacological treatments. Moreover, in recent years, guidelines have been developed for the management of pain in RACFs which cover the full range of identification, assessment and treatment issues. Pain management along with medication management is incorporated in the accreditation standards.¹⁰ Even so, we believe there is a strong case for including issues associated with pain management in the *Guidelines for Medication Management*. In large part this is simply because pain is such a common problem amongst nursing home residents and because medication is widely and frequently prescribed to manage it. Another reason for including a reference in the *Guidelines*, in particular the plain language version, is to help address the reluctance some residents feel about reporting pain and to help them better understand that in most instances pain can be managed. The Guidelines should also make clear that a resident and, where consent is given, their carer should be included in all aspects of pain management.¹¹

Medication Arrangements during Short-term Respite Stays

The existing Guidelines make no mention of medication arrangements during periods of respite, when a person stays temporarily in a RACF, perhaps because they need some extra care during a period of convalescence or because their carer is unavailable or needs a break. Because these stays are normally short it makes sense from the person's perspective to continue as far as possible with home routines. This is not always possible with medication arrangements, however, and the experience of carers is that forced change too often results in difficulties and confusion for residents, their families and carers.

All RACFs require a medication chart to be filled out by the person's own doctor close to the respite date and for the provision of sufficient of the person's medications for the duration of respite. Carers often manage medications at home with a dosette box. In respite, however, a RACF will normally require that all medicines be in original packaging or in a Webster (blister) type pack and will not normally permit loose medications to be used. To be forced to use Webster packs for a short term stay can be complex, costly and time consuming, for example

- ♦ an additional and/or longer doctor's consultation is likely to be required to complete the medication chart

⁹ The Australian Pain Society, *Pain in Residential Aged Care Facilities: Management Strategies*, August 2005, p1-2.

¹⁰ *The Pain Management Guidelines (PMG) Kit for Aged Care*, prepared by Edith Cowan University, funded by the Australian Department of Health and Ageing, 2007.

¹¹ This would be consistent with Guideline 23 in the *PMG Kit* (residents and their families should be included in all aspects of the pain management process); and the *Good Practice Principles* enunciated by the Australian Pain Society [2005] (a resident and his or her representative must be informed about, and actively involved in, pain assessment and management).

- ♦ the resident or carer will need to ensure that the doctor has provided sufficient repeat prescriptions for the length of stay and money will need to be found to fill these prescriptions in advance
- ♦ there may be a need to go to a different pharmacist if the regular pharmacist does not fill Webster packs
- ♦ pharmacists charge to fill the Webster pack (usually \$4-\$6 per week), and
- ♦ familiar medications may be substituted for other brands/generics or multiple lower dose pills without explanation to the older person or family.

It is acknowledged that Webster packs are cheaper, safer and more efficient for RACFs but staff need to be sensitive to families being unfamiliar with them and the extra time and money involved with compliance. It is important that RACFs give clear advice to people seeking respite (and their carers) on the steps they will need to take to get their medication into order before they enter the facility; and on medication arrangements that will apply in the facility once they have entered. Carers Australia suggests that a section in the *Guidelines* should highlight the need for RACFs to provide this type of advice. The plain language version should make these matters clear for people seeking respite and their carers.

F. n/a

G. The development of a plain language summary.

A plain language summary of the *Guidelines* is needed to make them accessible to residents or their carers. Most emphasis should be placed on a clear enunciation of residents' and carers' rights, expressed in a practical way, for example a resident and, where there is consent, their carer has a right to be consulted about any change in the resident's medication regime. The summary should highlight the opportunities for the resident and their carer to participate in decisions about medication, starting with the inclusion of information in the resident's medication chart. The summary could also advise on other sensible practices which a resident and their carer ought adopt, for example a resident self-administering medication should ensure that they have advised the RACF of the details of their medication.

H. Implementation and Education Strategy

For the benefit of a new or prospective resident and their carer it will be important that the *Guidelines for Medication Management* or their plain language summary are available with other key information about aged care. This information should be available nationally via the 'aged care gateway' including 1800 numbers and the aged care website. The same information, supplemented as needed by location specific information, should be provided by individual RACFs prior to entry and be readily available to residents and their carers.

