

Home Care Packages Program Guidelines – Consultation Draft

WINTRINGHAM SUBMISSION TO THE
Australian Government Department of Health & Ageing



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PREFACE

Wintringham welcomes the opportunity to comment upon aspects of the *Home Care Packages Program Guidelines*.

Wintringham's response to the Home Care Packages Program Guidelines will concentrate exclusively on the area we have expertise in, namely the elderly homeless.

Having said that, we believe that some of the responses that we have developed to the problem of delivering services to aged men and women who are homeless have clear implications to the development of a range of programmatic policy settings for the delivery of aged care services to all elderly people who do not fit neatly into existing mainstream groups.

The following paper concentrates on what appear to be unintended consequences of the guidelines on the elderly homeless and financially disadvantaged clients of what will become known as Home Care Packages.

Wintringham: some background information

Wintringham was established in 1989 as an independent not-for-profit welfare company to provide high quality aged care services to frail elderly homeless men and women. Today we provide a range of services to approximately 1,300 elderly people who are homeless or at risk of becoming homeless each night, including low and high care residential homes, community care packages, State funded support packages, a range of housing services and options, street based outreach work, advocacy services, as well as our work representing the interests of the homeless elderly on a variety of State and national ministerial advisory committees. More details about these services and further background to the company can be found at www.wintringham.org.au.

In 2011, Wintringham was awarded the United Nations Habitat Scroll of Honour, the first time an Australian organisation has achieved this award which is the highest award for human settlement provided by UN-Habitat.

The vision at the start of Wintringham was simple. The company would be a social justice organisation that would care for older homeless people whom the aged care industry had turned its back on.

Our view of social justice, and the rights that flow as a result of social justice, is that aged care and housing are basic and fundamental rights and should not be consequential on the personal values of a worker or an organisation. So, for Wintringham, older homeless people have a right to decent aged care services and housing simply because they are Australian citizens.

The elderly homeless remain one of the most disadvantaged and powerless groups in Australian society. At a time of life when most people would be enjoying their

retirement, elderly homeless men and women live outside mainstream society making do with inadequate food, clothing and housing.

In 2008, Wintringham Housing Limited, a wholly owned subsidiary of Wintringham, was established to concentrate exclusively on delivering housing services for the elderly poor.

Elderly and homeless: shifting the paradigm

At the time of the formation of Wintringham, many hundreds of elderly men and women were living and dying in homeless persons' night shelters unable to access mainstream aged care services even though these services were often run by Church and charitable organisations who received tax concessions in order to provide for the disadvantaged.

The prevailing view in the 1970's and 80's was that as these elderly folk were homeless, it was appropriate that they were in a homeless service. In short, these aged people were being seen as *homeless and elderly* and as such it was the responsibility of the homeless sector to provide for them. Wintringham reversed that expression, arguing that aged homeless people were *elderly and homeless*.

Changing the description of aged homeless people from being *homeless and elderly* to *elderly and homeless* is not merely semantics: it creates a new paradigm and a new way of thinking about the elderly homeless. It involves acknowledging that the person is aged and therefore entitled to normal aged care services. If we say they are homeless it perhaps makes some sense of the fact that they are living in a homeless persons' night shelter, but if we say that they are aged (and just happen to be homeless) then the next question surely is "why are they not part of the aged persons' service system?"

The principle that Wintringham has operated on from its inception is that the aged homeless should have the same right as any other elderly Australian to access mainstream aged care services.

The aged care system is not allowed to discriminate against any minority group on the basis of their ethnicity, religion or personal views. Why then should they not be required to make welcome the elderly homeless?

Unable to place our elderly homeless clients in mainstream aged care services, Wintringham resolved to build its own.

HOME CARE PACKAGES PROGRAM GUIDELINES

Excluded services and Items

Wintringham has a long history of provided Community Care Packages to homeless and financially disadvantaged clients. In fact, in 1989 Wintringham secured, through the agency of Minister Peter Staples, 50 Hostel Options packages delivering

community care into the Gordon House night shelter for homeless people. This was a direct precursor of today's community care model.

It has been essential that packages are highly flexible to meet the unique needs of this client group. We believe that one of the intentions of the move to Consumer Directed Care (CDC) is to *'assist providers and consumers to maximize the amount of choice and flexibility in delivery of packages'*.

Ironically, 'Excluded services and items' included in the draft of the Home Care Package Guidelines will reduce the control and flexibility that our disadvantaged clients have over their packages. More specifically, exclusions in the following 5 areas will have significant negative impacts on Wintringham clients:

- Purchase of food
- Travel and accommodation for holidays
- Entertainment activities, such as club memberships or tickets to sporting events
- Payment of respite fees
- Payment for services and items covered under the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS).

Purchase of food

The area of greatest concern from this list is purchase of food.

Many of Wintringham's clients have inadequate nutrition and do not have access to any means of cooking (i.e. no stove, hotplates or even a microwave). Other at-risk clients live in environments where it is unsafe to access the facilities available. This can be due to either poor quality buildings or the threatening nature of communal living areas. Preparation of meals in these environments is impossible, and the only way to ensure suitable nutrition for these clients is to provide delivered meals, or access to food through a local supermarket, pub or café.

Wintringham targets clients who are difficult to engage and are often resistant to services. The inclusion of purchased food for these clients can be perceived as a concrete and immediate improvement to their life. Therefore, it can be an important aspect of engagement between a client and a Wintringham worker in the early stages. For this reason, we see including food in our clients' packages as a powerful tool for engagement.

Providing affordable and nutritious home delivered meals to clients on packages has always been a challenge to community aged care providers. For the aged homeless population, the provision of at least one good meal a day is critical to their health and well-being.

Due to the importance of this issue Wintringham built an industrial kitchen in Avondale Heights with the capacity to provide flexible and affordable delivered meals to this often isolated and at-risk client group. This solution has been commended at Quality Visits and DoHA and recognized as an innovative and effective response to a difficult problem.

On some occasions the purchase of food through a local supermarket, pub or café is a preferred solution for a client with inadequate nutrition. This was the case with Fred:

Fred is in his 60s, prematurely aged from a rough and transient life. Fred was living in a poorly managed rooming house when he was referred to Wintringham for a Community Aged Care Package. Fred 's food was being stolen by the younger residents in the rooming house, and he often went hungry or relied upon fast food as he could not keep any food in his home.

Fred was suspicious of Wintringham's case manager when they first met, and did not like the idea of someone "butting into his life". After a few visits from his potential case manager Fred started to open up about his hunger and the issues with his food being stolen. Fred's eyes lit up at the idea of Wintringham helping with the provision of hot meals at a local café, ensuring Fred had access to suitable nutrition and an opportunity to engage with his local community. After only a few weeks the visiting nurse (through Royal District Nursing's Homeless Persons Program) commented that Fred's diabetes had improved, and ulcers which had been un-healed for over 6 months were beginning to improve.

The provision of meals was the start of a great relationship with Fred. After receiving meals for a few months Fred began to trust Wintringham. He agreed to let carers assist with washing his clothes and showering.

By providing food as part of the package, Fred was able to improve his nutrition, improve his health, and re-connect with his local community. Food was the key to improving his quality of life.

Ensuring adequate nutrition for homeless and financially disadvantaged clients is a critical component of their care and its definite exclusion from Home Care Packages would be devastating.

RECOMMENDATION 1

Wintringham very strongly recommends that this exclusion (purchase of food) is not applied to organisations that focus on financially disadvantaged and homeless clients.

Travel and accommodation for holidays

Wintringham have consistently seen significant benefits from providing individualised recreation programs for our clients and residents. Within Wintringham's residential programs we run 3 day holidays for up to 150 people per year. These holidays have always been popular because they provide homeless and financially disadvantaged people with the opportunity that they may have rarely, and in some cases never experienced.

However, it has not been easy to facilitate holidays for clients in our Community Aged Care programs. The upcoming introduction of CDC's generated significant

excitement amongst our recreation staff. This excitement was due to their misunderstanding that a CDC would enable clients to save up some of their package funds to put towards a long overdue holiday. The value of this can be seen in the following example:

Mary is a 68 year old Wintringham client on a Community Aged Care Package. She has an undiagnosed intellectual disability and was homeless and living in a rooming house when she was offered and accepted a package with Wintringham three years ago.

Mary is a Forgotten Australian having spent periods of time in an institution when a child. She has two adult children both with disabilities who were removed from her care and both now reside in foster homes in Echuca. Part of Mary's individualised care package was to meet a key goal she had to reunite with her two children whom she had not seen in many years. She had not been able to get herself to Echuca nor did she ever have the money to pay for the trip or accommodation if she was to visit. Hence she had no contact with her children.

Through the concerted efforts of Mary's case manager and the case managers of her children, Mary was assisted to have two short breaks in Echuca where she was able to spend time with her children. Mary's package covered the Wintringham staff member who accompanied her on the overnight trips and the accommodation in a local motel. If the package did not have the current flexibility to pay for this break Mary would definitely not have been able to reunite with her children.

Excluding travel and accommodation for holidays from Home Care Packages will prevent this exciting outcome for CDC clients.

RECOMMENDATION 2

Wintringham recommends that this exclusion (travel and accommodation for holidays) is not applied to organisations that focus on financially disadvantaged and homeless clients.

Entertainment activities, such as club memberships or tickets to sporting events

Facilitating each client's individual recreational interests results in an extremely broad range of activities. These include entertainment activities, such as club memberships and tickets to sporting events. An example of this is Don:

As a student in his high school swim team, Don loved sport and was recruited to play for Carlton Football Clubs under 19 team. After his playing days finished Don had a family and his recreational interest became supporting Carlton. He has fond memories of attending every match at Princess Park with his daughter who would fall asleep on his lap.

Don's life took a turn for the worse in his 40's when illness struck and his marriage broke down. With only a pension to survive on Don had to give up all his recreational interests. When commencing on a Community Aged Care Package with Wintringham, Don spoke fondly of his past, and the memories of sporting events. Recreation staff assisted Don to enjoy AFL matches, visit the MCG sports museum and swim weekly at the St Kilda Sea Baths. Being able to re-engage with these recreational pursuits of his past, led to improved mental health increased social engagement and connection to his local community. In short, Don's quality of life significantly improved. Don would have been unable to access these activities without the financial and case managed support of his Community Aged Care Package.

We are alarmed to see entertainment activities, such as club memberships and tickets to sporting events are excluded from Home Care Packages Program Guideline because Don and many Wintringham clients like him will be disadvantaged by this restriction.

RECOMMENDATION 3

Wintringham recommends that this exclusion (entertainment activities) is not applied to organisations that focus on financially disadvantaged and homeless clients.

Payment for services and items covered under the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS)

For Wintringham's clients, the purchase of PBS or MBS items can be an important aspect of care.

Clients who are homeless or financially disadvantaged may discontinue their PBS medication due to other financial pressures. Where non-medication could lead to undesirable medical or social consequences Wintringham has used funds from a client's aged care package to purchase their medication.

These instances are rare, however, having the flexibility to fund PBS or MBS items as part of a home care package for homeless clients is an important aspect of care.

RECOMMENDATION 4

Wintringham recommends that this exclusion is not applied to homeless clients, giving Wintringham, and similar organisations, the flexibility to purchase PBS and MBS items when essential for clients' well being.

Payment of respite fees

Payment of respite fees is a common use of package funds within Wintringham's existing Community Care programs. We don't believe that our clients use respite care any more frequently than mainstream Community Care clients, however, our financially disadvantaged clients can't afford the respite fees and they are not eligible for funding from Carer Respite.

Carer Respite provide valuable support to carers of elderly people living at home. In turn, this benefits those they care for by enabling them to access funding for respite in residential care. Unfortunately, most of our homeless and financially disadvantaged clients do not have carers, which makes them ineligible for this funding.

If the guideline remains as it is (i.e. preventing Wintringham from paying the respite fee from the Home Care Package) financially disadvantaged clients will be unintentionally excluded from Residential Care Respite.

RECOMMENDATION 5

Wintringham strongly recommends that excluding Respite fees from a CDC is inappropriate and should not be applied to organizations that focus on financially disadvantaged clients.

Fees in Community Care

As mentioned above, our clients struggle to meet their week-to-week financial commitments. Once the bills are paid, those in private rental, on a single, pension-only income, cannot afford to pay 17.5% of their pension as fees. We understand that the Hardship Supplement will be introduced into Community Care, however, the process required to determine individual eligibility for the Supplement is onerous and where no family or friends are available to assist the care recipient this usually becomes another Provider responsibility. We understand that consideration is being given to the Minister proclaiming certain Special Needs Groups as eligible for the Supplement – presumably without application – but we are concerned that these funds may be limited to specific packages designated for these Special Needs Clients – rather than being available to all care recipients who meet specified, but easily measured criteria.

RECOMMENDATION 6

Wintringham strongly recommends the payment of a Hardship Supplement to any care recipient whose income and assets are below a certain dollar value (ie assets <\$15,000 and pension only income). Those whose income and assets were above these amounts could still apply for consideration for a Hardship Supplement through the usual processes.

Viability Supplement

The difficulty that specialist providers have in delivering financially viable residential aged care services to elderly homeless people is replicated with community or home care services.

Home based care is built around central concepts of 'home' and 'family', neither of which are likely to have much direct relevance to homeless people, or indeed to those elderly people who are at grave risk of becoming homeless.

Wintringham's community care services have their roots in our Outreach teams who search out or follow up on leads concerning elderly people who are homeless. Our aim has always been to develop a suite of services that are instantly available to our outreach workers which they in turn can offer to their homeless clients. These services range from advice and support to housing and aged care services whether community based or residential.

The commonalities which unite most of our community clients are their experiences of absolute poverty, their consistent lack of family contact or support, and the instability of their housing.

It is readily apparent that managers of community care programs that deliver care to homeless people face different financial pressures to those in mainstream programs. Using a personal example, when my mother was in receipt of a CACP package, because the family was able to provide support, outings, clothing and a range of other items that a supportive family would unhesitatingly provide, the CACP package could concentrate on applying resources to enable mum to stay at home.

At Wintringham, most of our clients have no contact with anything like a supportive family, which means that the resources of the package have to cover items that it would be presumed would be picked up by the client's family. This, combined with the continual stress of inappropriate housing, such as caravans or boarding houses, results in a very different CACP program to those provided by mainstream providers.

RECOMMENDATION 7

Wintringham very strongly recommends that a Homeless Supplement is required to help address the imbalance of services provided to homeless clients as compared to other elderly people in the community.

Dementia Supplement

Wintringham are appreciative that new home care packages will be supported with a Dementia Supplement. We believe many of our clients should be entitled to the supplement as most of them have behaviours of concern. We congratulate the department for recognising that clients with behaviour issues present a higher cost of care for service providers at all care levels.

Of concern to Wintringham is the reliance on the Psychogeriatric Assessment Scales (PAS) as the preferred tool for assessing community clients' behavioural care needs. While we understand that PAS may well work in a mainstream client cohort, we are not satisfied that it is reliable with homeless clients who have atypical forms of dementia. Wintringham has a high proportion of clients with behaviours of concern

that are more related to brain injury, particularly alcohol related brain injury. As such we are concerned that the use of PAS exclusively for assessment of behaviour with community clients may inadvertently discriminate against our client's behavioural care needs.

Since the introduction of ACFI in Residential Aged Care, our clinical and care staff have found the PAS to be unreliable in terms of predicting our residents' behavioural care needs. Department representatives have themselves acknowledged our concerns with using PAS for our client group during 2009 – 2010 when a full ACFI review occurred at Wintringham.

Further to this, the Psychogeriatric Assessment Scales User Guide indicates that sufficient data has not yet been collected to use the PAS reliably for people with alcoholic dementia (which constitute a large cohort of Wintringham's clients). (<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-pas-guide.htm>)

RECOMMENDATION 8

Wintringham advises that the PAS is not a valid assessment tool for homeless clients with an alcohol related brain injury or dementia. We would ask that DoHA works with Wintringham to determine a more appropriate assessment tool or method.

We also note that the guidelines currently specify that behavioral assessment must be undertaken by a registered nurse, clinical nurse consultant, nurse practitioner or medical practitioner. Wintringham clients are supported in the community by Case Managers who have an approved tertiary qualification in Social Work, Nursing, Allied Health or Welfare. Given the expertise of our current case management group with extreme behaviors, Wintringham hopes that greater flexibility to who may complete the assessment will be offered; as we believe there will be an unnecessary additional cost imposed on some providers to be compliant with the draft behavioral assessment expectations.

SUMMARY

Wintringham, together with the Federal Government, established in 1989 the right of Elderly Homeless people to access the mainstream aged care program. While that victory for homeless people is still resonating around the aged care community, a fundamental problem continues to plague the delivery of these services. The problem is that the aged care system and all of the various alterations, additions, reforms and innovations are designed around the needs of an elderly person who has little in common with a homeless person.

Overall, Wintringham is very supportive of the new approach to home care packages outlined in the Consultation paper. Our recommended changes reflect what we believe to be unintended consequences for homeless and disadvantaged clients of reforms designed around more mainstream clients.

Wintringham would respectfully ask the Department of Health and Ageing take note of our concerns and the consequent recommendations and works with us to help ensure that the elderly homeless can continue to access appropriate aged care services.

Unless these recommendations are acted upon, the guidelines will unintentionally further disadvantage the elderly homeless and reduce the flexibility and control they have over their care.

Bryan Lipmann, AM
Chief Executive Officer
17 May 2013