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POST-DIAGNOSTIC COMMUNITY SERVICES

FOR PEOPLE LIVING WITH DEMENTIA IN AOTEAROA NEW ZEALAND

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for Dementia New Zealand
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Preface

Following a diagnosis, people with Dementia and their whanau often face a long and uncertain journey. The Dementia sector NGOs have long been a critical part of providing care, guidance and support to all of those throughout their journey with the illness.

In order to best inform the care provided, Dementia New Zealand resolved to obtain an up-to-date literature review and the New Zealand Dementia Foundation agreed to undertake this. We are delighted with the comprehensive review in this paper, and we thank Matthew Croucher, Matthew Chamberlain and Susan Gee for their magisterial review of this area of clinical practice. We commend their excellent work to everyone with an interest in this area of health care.

Dementia New Zealand would also like to sincerely thank the Lion Foundation for their financial support of this project.

In the review, Post-diagnostic dementia care is clearly shown to be helpful for both people with dementia and their whanau, and also may extend the period of time where the person is able to live in their own home. There is also scope to improve a person's cognitive function to some degree. There is now no doubt that such programmes should be offered to all people newly diagnosed with dementia. Providers of such services are now in a position to plan their suite of programmes accordingly, and we believe that proper funding for these should be made available, when service planning is undertaken.

Please read with interest and share with those who need to know.

Ngā manaakitanga

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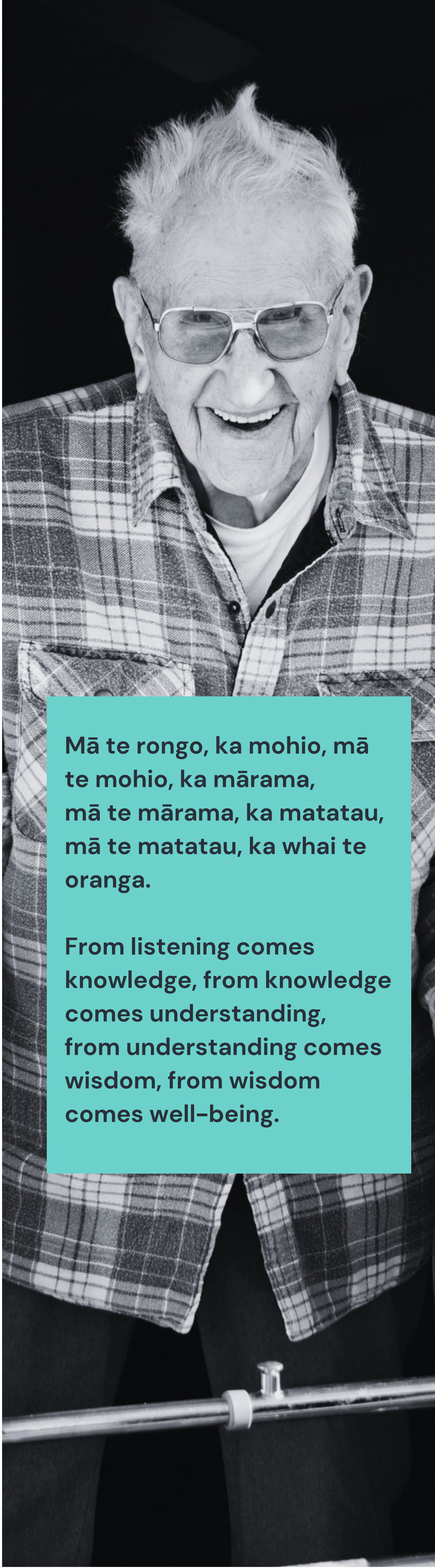

Mā te rongo, ka mohio, mā te mohio, ka mārama, mā te mārama, ka matatau, mā te matatau, ka whai te oranga.

From listening comes knowledge, from knowledge comes understanding, from understanding comes wisdom, from wisdom comes well-being.

Introduction

What does the research literature tell us is 'best practice' for post-diagnostic community services for people living with dementia and their care partners from the perspectives of people with lived experience, experts, service providers, and research findings?

Aotearoa New Zealand is not the first nation to seek to answer this question. Perhaps the pithiest definition of the goals of such services has been provided by the Irish Centre for Economic and Social Research on Dementia:

> *The main aim of post-diagnostic support services for dementia is: to help people to continue living well in the community; provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care."* (O'Shea 2017)

Accordingly, the first Dementia / Mate Wareware Action Plan (Mate Wareware Advisory Rōpū 2021), endorsed by the two largest political parties in Aotearoa New Zealand in their 2020 health manifestos and formally adopted by Cabinet in 2022, identifies the following actions in relation to post-diagnostic services that should be available to all people in our communities:

> - *Commission and/or deliver equitable, tailored, person-directed, culturally appropriate and quality assured support services for people with dementia/mate wareware, family and whānau, and care partners based on holistic health models such as Te Whare Tapa Whā, including as the first priorities for improvement:*
> - *At least 12 months' post-diagnosis support to equip people to live their best possible lives, including but not limited to:*
>   - *-information on what to expect, the services available and their rights,*
>   - *-tools and support to plan and prepare for the future,*
>   - *-support services to strengthen resilience and wellbeing,*
>   - *-Cognitive Stimulation Therapy and other proven interventions to maximise function, and*
>   - *-a long-term plan including referrals to ongoing services and supports.*
> - *Improve the design, quality and availability of the existing community and home-based services so they support people living with dementia/mate wareware to remain at home with autonomy, dignity, and independence.*
> - *Dementia/mate wareware navigation services to coordinate and support access to needed services including emergency support, so people have as smooth as possible a journey through the course of their dementia/mate wareware and get the services they need and that are right for them.*
> - *Support for family, whānau and care partners including information, education, support, and flexible, available and accessible respite services.*
> - *Dementia/mate wareware information that is freely available, in accessible formats, and available in te reo Māori."*

Is this outline put forward by the first Action Plan both necessary and sufficient for evidence-based best-practice post-diagnostic services for people affected by dementia in Aotearoa New Zealand? What are the best service delivery methods by which some of these aims should be met in this country?

A review commissioned to address these same questions from the scientific literature by the National Dementia Office of Ireland reached a pessimistic view:

> *"While there is a lot of activity in regard to post-diagnostic support across many countries, the evidence base with regard to the effectiveness of various interventions is at best ambiguous and at worst weak. Considerable inconsistency between study designs and methods prevents meaningful comparison across studies and undermines the validity of the evidence base. There are few proven and internationally accepted evidenced-based psychosocial interventions for people with early stage dementia living in the community. Although there are many examples of good practice, few interventions have been rigorously evaluated. The majority of supports fall into the category of potential benefit for people with dementia, due to conflicting results arising from weaknesses in study design. There is, therefore, little evidence to draw clear conclusions from in regard to optimal supports or combinations of support." (O'Shea 2017)*

A recent influential attempt to answer these questions adopted a person-centred approach by returning to the people at the coal-face of service provision in good practice sites in England and Wales, more than ten years after their national comprehensive and very well-funded strategy was launched (Bamford 2021). The authors identify that services should aim to increase understanding and management of dementia by people living with dementia as well as their care partners. Enhancing emotional and psychological well-being and providing practical support were also seen as key aims, underpinned by timely identification and management of needs and by provision of integrated support.

The UK's Alzheimer's Society has recently published its own report into the adequacy of post-diagnostic support in England, Wales and Northern Ireland (Arblaster 2022). Their method was to first carry out a literature review and then refine those findings by surveying nearly a thousand people with dementia and care partners. Eleven support needs were crystallised by this process: education, individualised support, emotional support, mental health support, maintaining independence, managing symptoms, improving cognition, enhancing social connectedness, linking in with peers, care partner support, and providing consistent and on-going support. Of these, the latter was endorsed by every respondent, and the largest signals for which needs were not being met by local services were for care partner support, mental health support, and on-going provision of consistent services. Poor access to and uptake of Cognitive Stimulation was noted, and the key component of care partner support that was identified was dementia service navigation. The report's key recommendations are context-specific, mainly relating to national dementia initiatives peculiar to the three surveyed nations of the UK such as the funded GP-based "Annual Dementia Review", however the top recommendation is more applicable: that each person with dementia and their care partner have access to a named (and culturally appropriate) dementia support worker.

Scotland has developed a very coherent set of strategic plans for dementia service development over the last 15 years including a focus on developing more effective post-diagnostic community services. The second national plan (from 2013-2016) took this as its main goal, based on the "5 Pillar Model of Post-Diagnostic Support" developed by Alzheimer Scotland (Alzheimer Scotland 2011). The essence of this plan is that all people diagnosed with dementia should receive the security, for a minimum of one year, of a named person who has the flexibility to work alongside them, their partner and family; to help them work through the five pillars: providing dementia psychoeducation, establishing peer support, planning for future decision-making via powers of attorney, planning for future care via advanced care planning, and enhancing community connections. This approach was widened by the third national plan (2017-2020) to include older and more frail people whose dementia was diagnosed in the context of significant co-morbidity and whose needs for post-diagnostic support revolve more around well-coordinated dementia-informed home-based support services and health care (The Scottish Government 2017)

In Australia, the COGNISANCE project run by the University of New South Wales' Centre for Healthy Brain Ageing seeks to co-design an evidence-based suite of free internet-based resources to support Australians newly diagnosed with dementia as well as their care partners and the health professionals with whom they are working. The group has yet to publish peer-reviewed summaries of their data but they have provided presentations and structured their website (www.forwardwithdementia.au) around their finding that people with dementia and their care partners in New South Wales want a 'one-stop shop' that can link them in with the following (Low 2022, Hevink 2021):

- Social support (such as support groups or assistance with family),
- Emotional support (such as counselling or more formal therapy),
- Health services (such as knowledgeable GP or Occupational Therapy input),
- Home-based community support services (such as help with transport or cleaning),
- Assistance to plan ahead (such as legal advice re EPOAs and health advice re Advanced Care Planning), and
- Support for brain health activities (such as diet and exercise) and general "living well with dementia" activities (such as clubs and community activities).

The New South Wales group also argues that post-diagnostic support for people living with dementia should be conceived of as rehabilitative, insofar as rehabilitation is "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (World Health Organization 2011). This is an important stance to take account of because it has been consistently advocated by Dementia Alliance International, a collaboration of people with dementia that provides support and advocacy in respect of their human rights and quality of life (Dementia Alliance International 2022). This organisation has strong representation from Australia and Aotearoa New Zealand and is currently chaired by New Zealander, Alister Robertson (Dementia Alliance International 2022).

Looking more generally, the only review of reviews looking at what people with dementia themselves have said about the services they want to receive that is relevant to this report validates the formulations reported above (Von Kutzleben 2012). The authors find that the clearest signals were that people with dementia wish to receive individualised care at all stages of their dementia journey, provided by people with the best knowledge and skills, communicated clearly, with continuity of care balanced against the possibility that their needs might change. A core goal was to maintain a sense of who they are and how they live their life, whether or not a coping strategy of denial and avoidance was adopted rather than a strategy of active and conscious adaptation. The most recent summary review that looked at both the aspirations of people with dementia and their care partners (Morrisby 2018) highlighted that services were often not available, especially in a timely fashion early in the dementia journey, that more personalised service offerings were more acceptable, that communication between different services was critical, that education about dementia as well as dementia service navigation were both important needs, and that peer-to-peer support was an important ingredient of effective services.

Insofar as the outputs of this report are recommendations in respect of how post-diagnostic services for people affected by dementia should be designed, they can be considered to be “guidelines” that explicate the content of the Dementia / Mate Wareware Action Plan. As such, a recently published discussion of how to enhance equity protections in dementia guidelines is germane. The authors sought to measure how the “protected characteristics relating to equity” relevant to dementia that are laid out in the UK’s Equality Act 2010 are treated by all national dementia guidelines extant at the time of publication (James 2022). These authors find all guidelines wanting and conclude that bearing the Act's “protected characteristics” in mind when constructing guidance at the national level is useful for advancing equity in respect of dementia care for those populations not well served by mainstream services. The characteristics they highlight are: age (including young-onset dementia), disability (including intellectual disability), ethnicity (including culture and language), religion, sex, sexual orientation, gender identity, and marital / partnership status.

Aim

Building on overseas contributions, this report provides an updated review of recent literature and analysis of best practice approaches for core services, in an attempt to reach optimistic and specific conclusions about what should be commissioned from and provided by Dementia New Zealand affiliates and related groups in Aotearoa New Zealand.

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Method

The preparatory strategy for this literature review was to survey the nature of community supports offered to people with dementia and their care partners by relevant community dementia organisations and public health systems, and to organise them by type into categories of service.

Because there is no internationally agreed 'blueprint' for what constitutes adequate or excellent community dementia services, the underlying assumption was that national services will have organically evolved to capture many of the elements of ideal services in response to community demand, therefore surveying them would yield the correct domains for literature review enquiry. The countries outside Aotearoa New Zealand that were surveyed were limited to English-speaking nations with broadly comparable health systems, for convenience and applicability of findings, that is: Canada, Wales, Scotland, Ireland, Northern Ireland, England, and Australia. Internet-based grey literature including national dementia organisation websites, advertising material, service provision frameworks, and national dementia strategies were parsed to shortlist the primary categories of community interventions offered. These were cross-checked against the prior knowledge held by the reviewers about prominent international models of community service provision (such as the Mittelman New York University Caregiver Intervention).

The final categories generated by this process were:

- Psychoeducation
- Emotional / personal support
- Dementia services navigation
- Modifying dementia progression
- Specific therapies (such as art therapy), and
- Occupational and social interventions (such the Dementia Café movement).

It was recognised that although these categories overlapped, nonetheless each was thought to contain a core idea that was sufficiently different from the others to allow literature searches to be conducted.

Literature reviews and meta-analyses of the research evidence base within each of these categories were then identified through database searching. The size of the literature was such that seeking to replicate other authors' review processes from the primary research papers was well beyond the scope of this review. Accordingly, in line with the Irish and English / Welsh contributions, this is a narrative review of reviews supplemented by direct qualitative examination of the literature where it has not already been collated by other authors for formal review. It is beyond the scope of this review to present effect size information from all quoted studies.

The databases that were probed were PsycInfo, MEDLINE, Embase (all via the University of Otago's OVID platform) and CINAHL (separately) because these overlapping libraries comprehensively cover the psychiatric, psychological, nursing and allied health English-language literature between them, collectively avoiding either an American or European bias. Key words relevant to each category were entered into each search engine followed by generic terminology for post-diagnostic support in the context of dementia care. For example, in the psychoeducation search, the following key words EDUCATION, PSYCHOEDUCATION, and INFORMATION were combined with DEMENTIA. Where this simple search strategy yielded large numbers of papers, limits were applied to identify reviews of various kinds (narrative, systematic, organisational, and quantitative) such as the REVIEW ARTICLES specifier provided by OVID. Specific models of intervention that were already known to the reviewers or which emerged in the course of the search were searched for by name, such as the "REACH OUT" programme, and Cochrane reviews were accessed where applicable.

The resultant papers were screened by reviewing abstracts. A snowball technique was employed to identify further articles by using the 'cited by' function provided by many journal libraries as well as hand-searches of references in relevant papers. Finally, each category's body of literature was supplemented by articles recommended for inclusion by supervisors. Recent intervention studies with suitable qualitative or quantitative data were included where they usefully expanded on the findings of the identified review papers.

As the information began to be organised, the 'occupational and social interventions' papers identified by the process were noted to wholly overlap with those identified within other categories and so were better considered alongside them rather than as a separate section. Furthermore, it became evident that two more topics needed their own searches and analysis:

- Multi-modal interventions
- Literature relating to populations of particular importance in the Aotearoa New Zealand context (for example, for Māori).

This then yielded the final seven sections presented in this report:

1. Psychoeducation

2. Emotional and personal support

3. Dementia services navigation

4. Modifying dementia progression

5. Other specific therapies

6. Multi-modal interventions

7. Special topics for service development in Aotearoa New Zealand.

After review, a determination was then made by the authors as to the strength of any service recommendations that arose from the evidence base, taking into account the strength of evidence from an evidence-based medical framework as well as from a pragmatic perspective in light of the political and social situation in Aotearoa New Zealand, as follows:

CORE

Considered to be an essential element of post-diagnostic services on the basis of the literature reviewed: a priority for resourcing.

INTERMEDIATE

Considered to be of intermediate importance for inclusion in post-diagnostic services on the basis of the literature reviewed: second tier priorities.

PERIPHERAL

Not considered to be essential for the provision of post-diagnostic dementia community services from an evidence-based perspective, but still relevant: for consideration if resources allow.

NOT INCLUDED

Out of scope

Services provided by community dementia NGOs not covered in this literature review.

Out of scope

Some services provided by community dementia NGOs were not able to be covered in this literature review.

Professional roles

One of the questions that arises in developing an evidence-based service delivery model for community dementia NGOs is whether a particular kind of health professional is particularly indicated for the kind of work required. It is notable that many of this country's community dementia organisations currently employ social workers as the base of their workforce. The core aims, field of practice, and methods central to Social Work can obviously bring benefits to people with dementia and their families and support networks. Accordingly, some social work goals and methods are discussed in the course of this review, for example enhancing social connectedness is a key goal of the Dementia Café and Meeting Centre initiatives covered in the Emotional / Personal Support section.

However, many of the clinical goals central to dementia services are not specific to one professional group even if they might be understood to be central to the scope of practice of a specific profession. These can be thought of as 'frequently employed goals or methods' of comprehensive care plans for people with dementia living in the community, such as couples work or marital therapy being a frequent component of providing personal and emotional support, or support to prepare EPOAs being an important goal from a case management perspective. The literature on post-diagnostic support services does not make an argument for any particular kind of health professional to be the key provider. Even the UK and Irish literature covering the case manager roles mandated in those countries does not specify that Dementia Advisers and Linkworkers need to be nurses - although many of them are as discussed in the Multi-Modal Interventions section of this review.

Accordingly, this literature review cannot present arguments for or against social work or any other health profession forming a core part of post-diagnostic services. That is a question that services must answer on other grounds.

Respite care

It was recognised from the outset that dementia community NGOs can and do provide day-care / respite services. There is certainly a literature on the importance of and beneficial outcomes from the provision of brief residential, day-care, and home-based respite services. However, these options are not something that any international authors nor indeed local dementia services in Aotearoa New Zealand have argued should be solely or even primarily provided by community dementia NGOs. Providing day-care programmes that have a secondary aim of enabling regular respite for care partners in addition to various therapeutic benefits for participants living with dementia may also be an important part of the local offering of some of our community dementia organisations, but it cannot be argued from the literature that such organisations must provide respite to achieve best practice standards. Respite is definitely a secondary component of some of the interventions that are reviewed in subsequent sections of this report.

The main recent published reviewers in the dementia respite care literature (Vandepitte 2016) were able to conclude that there is reasonable evidence for reductions in measures of care partner stress and burden and a signal for improved social connectedness, as well as reductions in measures of behavioural and psychological distress for people with dementia who participated in such programmes. They noted that the studies are very heterogenous and difficult to compare with each other so quantitative reviews have not been helpful and meta-analyses have not been possible. Locally, Alzheimers NZ and partners commissioned a report on respite services (Synergia 2019) in which the case is argued for significant improvements to respite service access in this country on the basis of its importance to care partners and its cost-effectiveness to the system as a whole.

Respite care is therefore an essential and evidence-based service, care-partner respite is clearly a secondary benefit of any programme that involves a person with dementia spending time engaging with a health professional or care worker in a programme away from home, and day-care respite already forms an important part of the suite of services provided by some community dementia NGOs in this country. Nevertheless, respite care does not fall within their unique services that were intended to be covered by the Dementia Mate Wareware Action Plan's "post-diagnostic services" action point. Therefore, respite services are not reviewed further by this project.

Meaningful activity community groups

Activity-based groups in community settings have become increasingly common offerings by dementia NGOs in Aotearoa New Zealand, ranging from dementia-friendly reading groups in public libraries to gardening in public gardens, with much else besides. The concept combines aspects of respite provision for care partners, since they are typically day programme activities for people with dementia, with enhancement of social connectedness, ‘stigma-busting’ by virtue of their location in the community hosted by community partners, and maintenance or enhancement of meaningful activity and positive self-image by virtue of participation in ‘normal’ service and recreational activities.

One of the country’s dementia community NGOs that has been particularly active in this arena published an evaluation of its offerings circa 2017 (Gee 2018), as well as a guide to the barriers and enablers of successful programme design and operation (Gee 2020). The most helpful review relevant to the meaningful activity aspect of this treatment mode was commissioned by the Australian Government (ARIIA, 2022). It concluded that there a range of benefits from provision of personalised meaningful activities for the well-being of people living with dementia, including improved sleep and reduced anxiety and stress.

However, no specific reviews have been published directly addressing the form of programme offered by some New Zealand dementia NGOs: a portfolio of community-based meaningful activity groups. Accordingly, this literature review cannot present arguments for or against these groups forming a core part of post-diagnostic services. A strong argument can be made for their importance in the field of offerings for people living with dementia and for the ‘naturalness’ of their fit within the purview of community dementia NGOs, but this conclusion is induced from the literature supporting personalised meaningful activity and social connectedness as therapeutic strategies for people with dementia, contextualised to local resources and opportunities. These programmes are endorsed by this report as important core services but they do not lend themselves to the narrative literature review method adopted by this report.

Community education

Many dementia community organisations offer education to external organisations or to the public. These are not post-diagnostic services so this literature review does not present arguments for them forming a core part of the activities of community dementia service providers, although strong justifications can be made.

Some community dementia organisations also champion formal 'dementia friendliness' / de-stigmatisation initiatives, generally Alzheimer Disease International’s “Dementia Friends” and “Dementia Friendly Accreditation” programmes. These are not post-diagnostic services for people living with dementia and therefore these initiatives also fall outside the domain of this report.

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CATEGORY 1

Psychoeducation

A programme that provides knowledge alongside emotional and motivational components to enable people living with dementia and their care partners to live well with dementia.

Psychoeducation

People living with dementia and their care partners alike highlight the value of learning more about the condition, in particular its causes, outcomes, and ways to manage it. Psychoeducation is considered to be an essential component of post-diagnostic programmes (for example, Whitlatch 2018 & Department of Health 2009).

Significant gaps have been particularly identified by care partners in respect of the information they received as part of standard diagnostic processes (Stokes 2014). Aotearoa New Zealand data support this and underscore that people can often feel that they do not have "enough" such information even when the diagnostic process has been expert and both written and verbal information has been given (Hitchcock 2019). There is clearly value in psychoeducation at multiple points on the dementia journey beyond the diagnostic moment, in other words, information transfer that is tailored to the needs of the person with dementia and their care partner rather than a one-off "one size fits all" approach (Kelly 2016).

A 'patient-centric' definition of psychoeducation holds that it is "*an intervention with systematic, structured, and didactic knowledge transfer for an illness and its treatment, integrating emotional and motivational aspects to enable patients to cope with the illness and to improve its treatment adherence and efficacy*" (Ekhtiari 2017). In this rather medicalised view, it is a tool to enable self-management of illness, a concept of growing importance over the last decade for health systems and communities worldwide, and one that can be argued to be of relevance in mild to moderate dementia at least. Two very thoughtful summaries of designing the contents of self-management approaches for dementia psychoeducation are presented in Mountain 2012 and Martin 2013.

There has been a separate movement over the last two decades towards a family care partner focus in general health care research, in which psychoeducation is "a method of working with families and carers who are supporting a person with [mental] illness with the aim of enhancing treatment outcomes by enabling those who are closest to the person to manage the issues that can arise or which may exacerbate the illness" (Brady 2017). This is consonant with the origins of many community dementia organisations: grass-roots support bodies created for and by family care partners.

In Aotearoa New Zealand, a collaboration of dementia stakeholders across the health regions of the country has published a consensus document suggesting the core components of dementia education for people with dementia and their care partners, as well as giving advice on aspects of delivery (National Dementia Framework Collaborative 2019). What does the literature have to add to this expert advice?

One issue affecting the ability of research to parse out the differential benefits of psychoeducation is that it is clearly a component of virtually any imaginable post-diagnostic intervention. A common finding in the literature is that many of the interventions studied are multi-component, which makes it difficult to separate out effects of the various sub-components (such as psychoeducation), however the signal is generally for positive benefits from those interventions where psychoeducation was an important organising principle for the intervention, even if other aims were also being met.

Psychoeducation appears to be a critical ingredient of multi-component interventions (Dickinson 2017) with a dose effect – the more the better (Huis in het Veld 2015).

A review focusing on outcomes for people with dementia themselves demonstrated that self-management aims and strategies common to other illness settings can be incorporated into dementia psychoeducation for people with dementia. This includes components such as information about dementia to enable development of more adaptive illness representations, discussion of stigma management to enhance people's ability to attract social support, and learning how to use memory aids (Quinn 2016). The studies reviewed by these authors highlighted the benefits of group treatment sessions as ways of sharing knowledge, building relationships, and positioning each person with dementia as an expert contributor, not merely a recipient of psychoeducation.

From the perspective of studies evaluating care partners effects there is also agreement that psychoeducation should focus on developing knowledge about dementia and skills development, with one review concluding that key components include the psychoeducation being underpinned by a theoretical foundation, the inclusion of care partners, and a group delivery format (Dickinson 2017).

There are conflicting signals in the literature in respect of whether interventions that are primarily built around imparting information and knowledge produce wider benefits beyond increases in knowledge. For example, one reviewer's conclusion is that this is not the case for care partners (Huis in het Veld 2015), yet one of the few randomised controlled trials in this part of the literature (Seike 2021) was able to show a benefit on care partners' self-appraisals of their coping skills, sense of fulfilment, and mood from a six-session programme aimed primarily at psychoeducation. One review has gone so far as to suggest that psychoeducation may be the most potent single intervention to lower care partner burden, with benefits for care partner stress and depression in particular (Teahan 2020).

The most recent comprehensive literature review in respect of psychoeducation (Miles 2020) outlines the heterogeneity of the research literature on social support interventions overall and the authors are disappointed that there is no gold standard for provision of patient and care partner information and support given that it is widely accepted as an important standard of care. Within the research that is available however, they nevertheless found generally positive effects for both people with dementia and their care partners, especially for depression and anxiety. A more detailed but earlier systematic review and meta-analysis was able to show moderate benefit for care partner stress and a small benefit for relieving care partner depression (Jensen 2015). In line with these findings, a more narrative review that included studies of specific skill-building psychoeducational initiatives for care partners concluded that there were benefits in respect of care partner measures of well-being, quality of life, attitudes towards care giving, and measures of psychological illness (Elvish 2013).

A report for the dementia sector in Ireland examining the outcomes of pilots of several post-diagnostic service options (Genio 2016) noted that in their setting, individual provision of post-diagnostic information was more effective than the group formats trials. An earlier systematic review (including a meta-analysis of three studies that measured care partner stress using the Zarit Carer Burden Scale) could not conclude that there was clear evidence of benefit using the Zarit but did find reasonable evidence that advice and information services were beneficial in terms of reducing neuropsychiatric symptoms for people with dementia as well as carer stress, especially as part of a multimodal intervention package (Corbett 2012).

The REACH programme is a manualised intervention that was championed by the US National Institutes of Health from the early 2000s. This comprised a programme of structured 1:1 face-to-face and telephone care partner training sessions delivered by health professionals supplemented by a small number of group sessions by telephone. The overall focus was on enhancing knowledge and problem-solving, so although there are ‘support’ goals and measures, the primary intervention is best viewed as psychoeducation. Effectiveness was demonstrated in respect of lowered care partner depression and improved quality of life and a particular strength was the multi-site, multi-ethnicity design (Belle 2006 & Elliott 2010). Modifications were successfully made to enable less-trained workers to deliver the intervention via fewer sessions (REACH-OUT, Burgio 2009) and to tailor the programme for use with retired service people (REACH-VA, Nichols 2011) and the programme continues to be used in several US settings.

Lucero 2019 reviewed research into different types of media used to reach dementia care partners for psychoeducation, such as telephone calls, websites, and email, and found that the best evidence was for more personalised contact (by telephone), perhaps because this enables information to be more tailored to the situation they actually find themselves in. This was also highlighted by a similar review (Sztramko 2020) which found that although there is some evidence to support the use of online education tools on care partners’ mental health, there is a need for “tailored, stage specific information applicable to the care partner’s situation”. This lesson is underscored by an earlier systematic review (Lauriks 2007) that analysed the contents of multiple dementia information websites, many of which were extensive and contained high quality information. The authors found that the guidance available was still too generic, as well as being focussed more on care partner needs rather than on those of the person with dementia. Overall, there was no strong evidence for the benefits of individualised approaches using technology, certainly not in contrast with the more traditional method of using a group.

Summary: Psychoeducation

Psychoeducation for people living with dementia and their care partners is an established standard of care. It is also something that has always formed a part of New Zealand’s community services for people affected by dementia.

- There is evidence for the benefit of psychoeducation initiatives on self-efficacy and quality of life measures across a range of disorders, including dementia.
- There is not enough evidence to identify a standardised delivery method for education in the dementia setting (Miles 2020). This has led to the development of a many different models. This diversity may also, in part, reflect the need for bespoke educational programmes that are responsive to the local sociocultural milieu.
- Including psychoeducation in multi-component group-based programmes for people living with dementia and their care partners has been identified by many researchers as standard practice internationally.

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CATEGORY 2

Emotional / personal support

The provision of emotional and personal support by peers, health professionals, and community dementia organisations.

Personal support

Dementia management guidelines recognise that the personal and emotional support of people who have received a new diagnosis of dementia and for their family care partners is important (for example, American Psychiatric Association 2007).

Improving access to such services was one of the central aims of the English / Welsh National Dementia Strategy (Department of Health 2009). "Support" can be understood to pertain to almost any of the domains of this literature review but for the purpose of this section, the focus is narrowed to the provision of emotional and personal support by peers, health professionals, and community dementia organisations. The provision of person-to-person emotional support to people with dementia and their care partners is perhaps so obvious a need and so intrinsic to health and social care providers' practice that it is difficult to separate out from other interventions from a research perspective. Nevertheless, evidence does exist that making efforts to address it is beneficial, with most such evidence being in respect of care partner programmes.

Care partners

A recent comprehensive review of the literature mapping care partners' support needs organised them into four categories: the care partner as a person, managing being a care partner, providing care, and knowledge of dementia (Clemmensen 2021). The first category and to a lesser degree the second map to this "emotional and personal support" domain. In more detail, these two categories were noted by the authors to include:

- help to cope with guilt and with stigma,
- help with feeling alone and isolated,
- help with the care partner's own mental and physical needs,
- learning how to solve problems constructively, especially conflicts with the person with dementia and with family and friends,
- learning to cope with changes in the person with dementia's behaviour and personality, and
- learning how to adjust to their new role as a care partner.

As expected, Aotearoa New Zealand data back up care partners' need for this aspect of support, for example the themes of "I find it very hard" and "the partners are dealing with a heck of a lot" emerged as key findings from one qualitative follow-up study of couples seen in a Memory Clinic (Hitchcock 2019).

Other studies have examined methods of delivery of support in detail. A review of interventions aimed at improving the self-efficacy of people with dementia and care partners casts doubt on whether online or telephone methods of delivery were as methods (Tang 2016). On the other hand, a more specific review with the primary aim of assessing the effectiveness of online support interventions found good evidence for a moderate effect size on a range of outcomes, but this was strongest for multi-component rather than online interventions with narrower scope (Etxeberria 2021).

A more recent, very rigorous review covering a large range of care partner interventions was able to shed light on what kinds of benefits are typically measured by researchers and how these are affected by different categories of intervention (Walter 2020). These authors report that few studies have examined the effect of providing emotional / personal support in isolation, and those that have are only able to demonstrate effects on self-rated (care partner) ability and knowledge. Strong benefits across a broader range of outcomes (care partner burden, depression, anxiety, subjective well-being; symptoms experienced by the person with dementia; and delayed entry into aged residential care) were only robustly demonstrated for formal multi-modal interventions in this review. The particular benefit of multi-modal interventions for care partner quality of life was replicated by another paper that used a meta-analysis method (Lee 2019), although intriguingly, they also report evidence that complementary therapies (massage / therapeutic touch and yoga / meditation) were more clearly beneficial than more traditional interventions such as Cognitive Behaviour Therapy.

One meta-review was able to analyse studies focussing on supporting the psychological well-being of care partners using self-management strategies (Huis in het Veld 2015) described a range from formal interventions such as psychotherapy to informal "general support". Benefits were demonstrated overall for relieving stress and distress and improving social outcomes, but not clearly in respect of reduced care partner burden, depression, and anxiety, or for improving coping skills or knowledge. Usefully, they noted a dose effect with the longer the duration of an intervention, the stronger its effect.

In light of this review, literature examining specific psychotherapeutic interventions offered to support people was examined. Cognitive behaviour therapy appears to be less commonly used as a pure intervention than are CBT-informed techniques formally embedded in broader treatment programmes, probably because this overcomes the resource problem of relying on clinical psychologists and other skilled but scarce CBT practitioners (Cheng 2019). Together, these CBT approaches were highlighted in one review as being more beneficial than other methods in terms of measures of care partner mental health outcomes (Wiegelmann 2021). Mindfulness-based cognitive therapy delivered in group settings to care partners (often supplemented by individual telephone contacts) has also been robustly associated with reduced carer stress, with possible additional benefits on care partner depression and anxiety (Chacko 2022).

The New York University Caregiver Intervention (NYUCI) is a key intervention to discuss in this section because although it is a multi-modal programme, it was developed to support spousal care partners with a core focus on their emotional well-being. It is of note because it is particularly well-characterised and researched and because it has attracted significant investment in several sites in the United States. The focus on spouses has since been broadened to include adult children care partners.

The spouse programme has demonstrated efficacy to improve care partner well-being, improve their ability to cope with behaviours they find challenging, reduce depression, and improve satisfaction with social supports, and via these effects to delay entry into aged residential care for their partner with dementia by about 28% compared with control dyads whose spouses did not receive the programme (Mittelman 2006). Delayed onset of negative health effects from caregiving as measured by self-rated health (with an effect size of 0.23) was also demonstrated and, less convincingly, a reduced number of health problems over time compared to control dyad spouses (Mittelman 2007).

The NYUCI adult-child caregiver programme has also demonstrated an ability to delay entry into aged residential care for the parent with dementia (by 50% over two years of follow-up, Gaugler 2013), reduce care partner depression, and improve care partner reactions to behaviours they find challenging, but it did not lead to improved social support or to reduced secondary stressors such as family conflict, perhaps because participants often preferred individual input rather than family sessions from the range of options available to them in the programme (Gaugler 2018). A health economic modelling exercise estimated very significant potential benefits from applying the programme to a state-wide setting (Minnesota, Long 2014) and the State of New York Department of Health formally rolled the programme out for similar reasons nearly ten years ago. It has since been adopted by a number of other jurisdictions in partnership with NYU Langone.

An intriguing intervention that does not seem to have been studied as a stand-alone measure is the provision of a dementia-specific helpline (as opposed to studies of various interventions delivered by telephone, which have been studied).These are now available 24/7 in the USA, Scotland, and, from 2022 in Australia, with lesser coverage in many jurisdictions. Professor Mittelman, developer of the NYUCI has indicated that their intervention has always included the promise that participants in their structured programme are permanently welcome to phone the programme’s helpline. This service is apparently seldom used by ex-participants but the fact that it is available has been highlighted by care partners as being beneficial to them (Mittelman 2016).

People living with dementia

There is a bias in the “personal and emotional support” literature: few authors examine formal post-diagnostic community programmes attempting to meet the personal and emotional support needs of people actually living with dementia. Unlike some other disorders, such as depression or cancer, care partner needs have always been accepted to be core aims for services and researchers alike; the concept of needing to ‘care for the caregiver’ has always been central to dementia community services.

Nevertheless, one paper attempting to review all interventions that might be used to slow the progression of Alzheimer's disease did include a brief review of studies pertaining to the social networks of people with dementia (Nelson 2015). Although the sociological literature relating to dementia is mostly not organised in respect of effects of interventions on dementia progression, the authors point out that loneliness and a lack of social connectedness is an established risk factor for dementia. The authors conclude that:

> **People with dementia have highlighted "company" as one of their most frequent unmet needs, and evidence exists that support groups designed for people with dementia can improve their quality of life and mood, and reduce behaviours that others find challenging.**

In terms of more psychotherapeutic programmes, a systematic review of such interventions 'for' dementia (as opposed to specific mental illnesses with which people with dementia may concomitantly experience) identified that CBT was the majority mode researched and that the main treatment effect demonstrated was reduction in depressive symptoms, although perhaps less effectively when these reached the threshold of a Major Depressive Episode (Sukhawathanakul 2021). Moreover, meaning-focussed and problem-solving interventions were more likely to be effective out of the psychotherapy studies reviewed.

Combined support

The most comprehensive review in the area of personal and social support for people affected by dementia is a meta-review of literature reviews and meta-analyses covering 25 years of the literature up to 2014 (Gilhooly 2016). The authors conclude that:

> **The evidence suggests that both care partners and people with dementia derive most benefit, as measured by general mental health and depression scales, from interventions that focus on managing problems, developing acceptance, or on providing 'pure' social-emotional support.**

They add that the methods of delivery vary from less structured support groups to formal multi-modal interventions, and that joint attendance by both parties in the care dyad was beneficial.

When such joint models were first being adopted, they were a new concept. The two best examples both originate in Holland and although both are multi-modal, strictly speaking, the purposeful enablement of peer support is so central to both concepts that they are reviewed in this section.

The Dementia Café or Memory Café movement first originated in the

Netherlands in 1997 as "Alzheimer Cafés". A key feature was that both the person with dementia and their care partner attend, a somewhat novel approach at the time. Meetings are typically monthly, combine peer support with semi-structured psychoeducation, and occur in a 'normal' community setting such as a community hall or public library, although some have been set up in aged residential care environments (the concept is described by the founder of the idea, Dutch clinical psychologist Bère Miesen in Miesen 2004). The concept has been standardised and exported to a range of countries in some form, arriving in the UK in 2000 and in Australia in 2002.

A typical session would include a period of unstructured socialising with refreshments, an educational segment (such as a video, interview, or talk), a short break, a question-and-answer session, and a final period of socialisation. The meeting is hosted by a team made up of clinicians and care partners, with a particular emphasis on involving knowledgeable dyads of people affected by dementia who are comfortable to talk openly about dementia including its emotional impact on them. The emphasis is on providing a safe space in which to talk realistically about the condition and how to live as well as possible despite its challenges (Jones 2011). Some cafés substitute the educational activity and its related Q&A time with a group activity such as music or arts and craft (Akhtar 2017). As an intervention, dementia cafés clearly meet personal and emotional support and psychoeducation goals but the emphasis of both content and form is on “Living Well” and maintaining engagement with real life in real-world settings.

The concept has only been studied in relation to local café initiatives and with qualitative methods. In Australia for example, care partner participants from four Perth cafés reported psychosocial well-being benefits for the dyads involved, with an emphasis on the care partners' well-being (Protoolis 2021); dyads from three “Memory Lane Cafés” in Victoria reported benefits in respect of social inclusion and well-being whilst staff reported the added benefit of linking people with the supports they could benefit from via contacts made in the café meetings (Dow 2011); and Alzheimer’s Victoria reported high participant endorsement of the programme as evidenced by large numbers of committed attendees (Mather 2006).

Another Dutch model with an older pedigree is the "Meeting Centre" initiative which began in Amsterdam in 2003, based in Vrije University. A review of the supporting literature (up to 2016) is presented in the guidebook for the UK’s version of the programme (Brooker 2017). The essence of the concept is for a day programme for people with dementia (including a variety of evidence-based social, physical, arts, and cognitive activities) combined with a family care partner psychoeducation group for a shorter period of time on the same day in the same venue, facilitated by the same team. Joint social activities for both members of each dyad are also held, and individual counselling / case management meetings are also possible.

A Meeting Centre serves a community of around 5000 people and operates for different but continuous cohorts on each day of the week, and the whole endeavour is underpinned by a coherent model that seeks to describe the process of adjusting to the challenges posed by dementia (the “Adjusting to Change” model) as well as a person-centred values system.

Dutch research in Amsterdam and

subsequently with centres nationwide has demonstrated that the system is acceptable to service users; it results in reduced apathy, improved social behaviour, and reduced depression for people with dementia; care partner confidence increases and carer burden measures decreases; and entry into aged residential care is delayed compared to 'usual-care' day programmes (Brooker 2017). As a result, there are now Meeting Centre Programmes in well over 100 sites in The Netherlands.

The MEETINGDEM project was set up by the EU Joint Programme for Neurodegenerative Disease Research to oversee nine pilot Meeting Centre programmes in the UK, Poland, and Italy, however its results were disappointing. Satisfaction was high (Szcześniak 2021) but although the data collected suggested care partner benefits such as lower carer burden (especially in Italy), the more extensive outcomes demonstrated in The Netherlands for care partners were unable to be replicated (Evans 2020). On the other hand, benefits for people with dementia were translated, especially for measures of positive affect, belonging, and quality of life; and there was a dose effect between attendance and improved neuropsychiatric symptoms (Brooker 2018).

It is worth reporting that a single review has specifically sought to pool data on social support group interventions for people with dementia given the recognition that groups such as Dementia Cafés were common and the academic literature contained an increasing number of papers describing them (Leung 2015). Despite identifying 31 studies, only two were randomised controlled trials and those two could not be meta-analysed because their designs were too different. Both found well-being related benefits but neither were similar to a Dementia café style group.

A review of multi-modal interventions overall also notably concluded that all interventions with strong social elements seem to confer benefits on participants but it is difficult to parse out the differential effects of the social / group component versus the formal activities offered in that context (McDermott 2019).

Summary: Emotional and personal support

In summary, the literature identified in this part of the review supports the broad conclusions that:

- People with dementia and their care partners have personal and emotional support needs over and above their need for more practical assistance.
- Formal, purposeful support interventions are more effective than informal interventions, for example, programmes using a structured and/or psychotherapeutically-informed approach delivered by trained staff.
- There would appear to be a ‘dose effect’ such that more is better.
- Programmes that encourage joint attendance by people with dementia and their care partners are worth considering, albeit possibly with each party attending different tailored components of such sessions.

- Group sessions are effective, and telephone or other digital media are likely to operate better as adjuncts rather than as core delivery methods.
- Resources spent on this kind of support may pay for themselves, particularly in terms of delayed entry into residential care.
- The value of permanent access to a telephone service for on-going advice and support should also be considered once a dyad has worked through the core part of any time-limited programme.

Therefore, interventions that specifically seek to provide emotional and personal support should be considered to be a core component of community services for people whose lives are affected by dementia, either as stand-alone interventions or explicitly woven in to multi-component strategies.

There is descriptive evidence for the acceptability and benefits of both the Dementia Café and Meeting Centre models that reinforces the place these similar programmes could have in respect of the post-diagnostic needs of people with dementia and their care partners. However, there is insufficient evidence to suggest either specific model should form a core feature of post-diagnostic community NGO services. Key elements are worth reproducing: developing a coherent underlying conceptual model for a programme, involving both members of the dyad, adopting a structured approach to sessions, and marketing and hosting the programme in a non-stigmatising and person-centred way.

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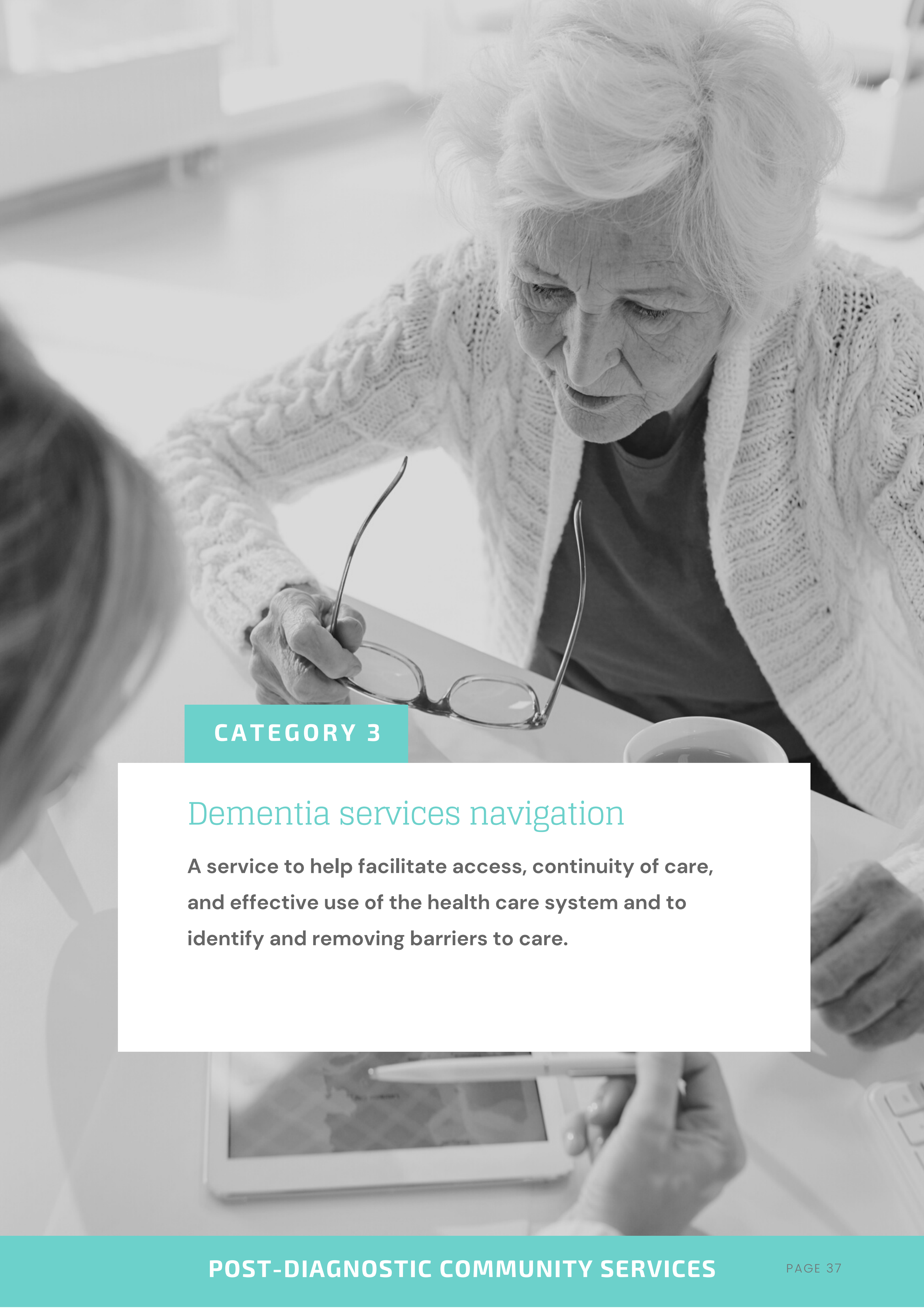

CATEGORY 3

Dementia services navigation

A service to help facilitate access, continuity of care, and effective use of the health care system and to identify and removing barriers to care.

Service Navigation

Dementia services navigation provides the guidance that people living with dementia and those that support them need to access services that are best suited to help them, at all stages of their dementia journey. Navigators must be familiar with the local map of dementia services, have general knowledge of the potential pitfalls and highlights intrinsic to dementia, and obtain an individualised understanding of the people requiring assistance.

The following is a published definition:

> *"… an individual or a team engaging in specific activities that include the following concepts: 1) facilitating access to health-related programs and social services for [people with dementia and their families and caregivers]; 2) promoting and facilitating continuity of care; 3) identifying and removing barriers to care; and 4) effective and efficient use of the health care system for [people with dementia, their families and caregivers, and health practitioners]." (after Carter 2018).*

In Aotearoa New Zealand, dementia service navigation is theoretically available from a range of sources, including:

- NGOs working in the dementia space, primarily Dementia NZ affiliates and Alzheimers NZ members, but also specific programmes run by other providers such as Presbyterian Support's Enliven services or some iwi-based kaupapa Māori kaumātua services,
- General Practices,
- Various 'Complex Case' programmes running in different Primary Health Organisations,
- Needs Assessment and Service Coordination agencies operating in the Disability Support Services funding space utilising "interRAI" needs assessments, and
- Older Persons Health (geriatrics) and Mental Health Services for Older Persons (psychogeriatrics) secondary care teams.

The main limits of this situation include:

- No individual, family or whānau is likely to have a sole named navigator for the duration of their dementia journey, be that an individual or even a service,
- Many of these sources are only available to people who are currently 'active cases' within a service,
- Service users often do not understand that 'dementia service navigation' is something that they can access even when it available to them in principle, and
- Providers differ greatly in the breadth, depth, and currency of knowledge they have of the dementia supports available locally and how to access them.

The essence of the argument for why health navigation might be important for people affected by dementia is that the field of available services is complex, the needs experienced by people living with dementia and their care partners varies significantly with progression of the illness, and amongst other barriers, the health literacy and self-efficacy of service users is lowered by the condition itself and the stress it creates (Doucet 2021).

The most comprehensive review of navigation services for dementia is a formal Canadian Health Technology Review (Banerjee 2021). It could not demonstrate a striking difference in clinical outcomes for people receiving dementia health navigation (called "care coordination" in this paper) versus 'standard care' other than reduced measures of behaviours that care partners found challenging. The authors do report a promising single published economic analysis which demonstrated net cost savings compared to usual care, however this is based on a German nurse-led dementia care management programme which included provision of home-based treatment in addition to service navigation (Michalowsky 2019), an intervention more similar to the Admiral Nurse and Dementia Advisor models discussed in the multi-modal interventions section of this report.

The main findings of the three systematic reviews surveyed as part of this health technology assessment were:

- There was weak evidence that service navigation might be associated with improved quality of life and fewer emergency presentations to hospital for people with dementia. (Butler 2020's US review summarises its analysis by stating that both have "low-strength evidence".)
- That it is reasonable to continue to attempt to use service navigation programmes to delay entry into aged residential care (Australian review, RR of 0.66 for institutionalisation compared to usual care, Lee 2020);
- That a key to realising better outcomes from navigation may be to pay more attention to service users' preferences (UK review, Backhouse 2017).

The importance of a navigation role was highlighted by a study within the European "Actifcare" project, which seeks to enunciate a European best practice suite of post-diagnostic services for people affected by dementia, specifying that an approachable and constant person (or organisation) should be available to coordinate the right services for each person and to link informal and formal care systems (Broda 2017). This report specifically questioned the ability of general practitioners to fulfil this role despite their ideal position in many European health systems, on the basis that they lack the necessary skills and/or resources for such a pivotal role.

A unique approach worth noting is "DEM-DISC" (DEMentia Digital Interactive Social Chart), a digital interactive chart enabling Dutch service users to access customised advice about local services. A small RCT was able to demonstrate increased competence as reported by care partners and a lower proportion of unmet needs for people using the tool (van Mierlo 2015).

Dementia service navigation is an intrinsic, perhaps even main role for the UK's Dementia Adviser and to some extent Admiral Nurse services. A review of international approaches to designing dementia strategies (O'Shea 2017) records that the Dementia Adviser service was explicitly designed to meet gaps in access to information, advice and signposting to enable them to live well and make informed decisions about their lives. This review will discuss these UK roles as examples of case management services in the “Multi-modal Interventions” section of this paper.

An American model particularly worth noting because of its potential scalability and cost-effectiveness within the US Medicare / Medicaid context relied upon an innovative workforce made up of non-professional healthcare workers who were trained to become dementia “Care Team Navigators”, backed up by a small team including a senior nurse, social worker, and pharmacist. The CTN role was to support 50-60 dyads comprising people with dementia and their main care partner via regular phone and internet contact, with a focus on navigating access to freely available web-based resources as well as real-world services. This “Dementia Care Ecosystem” approach was developed by the University of California in San Francisco’s Memory and Aging Center in 2013. A two-site RCT demonstrated improved quality of life for people with dementia and improved measures of care partner well-being over twelve months in a cost-effective manner (Possin 2019). It is now operating in eight centres around the United States and a range of reports have been published focussing on specific contexts including care giving during the COVID pandemic, advanced care planning / negotiating goals of care, and managing the financial abuse of people with dementia. Although the model offers more than ‘pure’ service navigation since management strategies were able to be suggested and followed-up by the CTNs (as evidenced in related publications), it is firmly based around a service navigation model.

Summary: Navigation

There are sound arguments underpinning why dementia service navigation should be helpful but there are a myriad of models for providing these kinds of services. This Is not unexpected given the need to tailor these services to the health service environments in which they operate.

Navigation services are well received by people living with dementia and their family care-partners, but benefits in clinical outcomes are difficult to demonstrate. There are signals that these services may reduce or delay utilisation of the services required once home-based care has broken down, such as for hospital admissions and entry into aged residential care, but clear quantification of these benefits has been elusive. This is not surprising given the lengthy time period and large number of participants that would be required to show meaningful differences between dementia service navigation and 'standard care': dementia only slowly precipitates these expensive outcomes and many factors other than qualities of the care package strongly influence the decision that home-based care is no longer appropriate.

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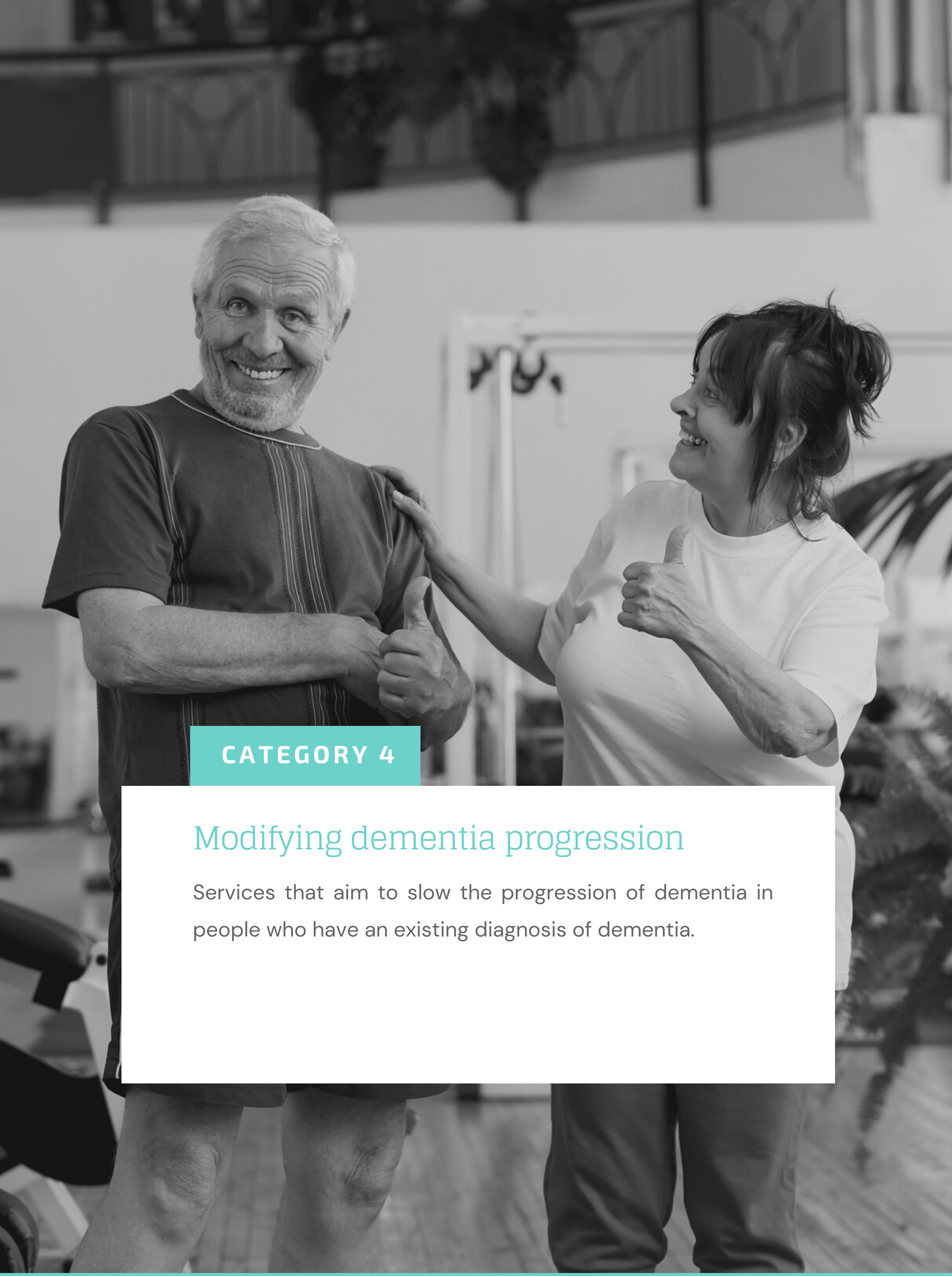

CATEGORY 4

Modifying dementia progression

Services that aim to slow the progression of dementia in people who have an existing diagnosis of dementia.

Modifying dementia progression

One of the potential management aims of community services for people after a diagnosis of dementia is to assist them to engage in behaviours that may mitigate the progression of their dementia condition.

Theoretically this could cover everything from developing new social relationships to reducing alcohol intake. In practice, social and psychological goals are usually bundled up with the other interventions reviewed in this report (such as personal / social support and psychoeducation). This section restricts itself to the literature covering attempts to affect the progression of cognitive impairment via:

- diet,
- exercise, and
- cognitive stimulation.

These are important facets of standard primary prevention programmes as well as being feasible offerings by community services for people with dementia.

Whilst there is a great deal of literature based on large prospective cohort studies concerning the primary prevention of dementia, there is less direct literature on modifying progression post-diagnosis and even less on programmes designed to achieve this aim offered by community services such as dementia NGOs.

Nevertheless, many practitioners believe that the same general advice generated from the primary prevention literature may be of benefit to people who have been diagnosed with dementia, albeit perhaps more weighted towards their beneficial effects on general health rather than slowing cognitive decline per se. Some dementia community NGOs have adopted a focus on these measures beyond providing information sessions that cover brain health promotion, for example the Minds in Motion® exercise programme developed by the Alzheimer Society of Canada.

One of the key directions of primary prevention literature, in particular the Worldwide FINGERS movement, is toward multi-component interventions that assemble dietary, exercise, and cognitive stimulation activities (plus others) into an organised 'bundle'. It would not be surprising if attention eventually turned in that direction in the literature on modifying progression, but it has not done so yet.

Diet

No examples of specific dietary interventions run by dementia community organisations were uncovered in the grey literature review for this topic. In Aotearoa New Zealand, an example of a service with peripheral relevance to the issue is the mothballed Senior Chef programme (or equivalents) in which small groups of older people were able to attend a series of hands-on workshops that encouraged a more positive attitude toward and improved skills in relation to meal planning and preparation. No dementia-specific service appears to have been offered. A further example would be the inclusion of cooking a meal or snack as part of a dementia-specific day programme or community engagement group. Whilst these programmes might encourage a healthier relationship with diet, they are not aimed at modifying the progression of dementia.

The main systematic review in this area considered 18 randomised clinical trials of single nutrient and multi-nutrient formulations including a couple of so-called "medical foods", as well as dietary counselling in the context of Alzheimer's dementia (Vlachos 2019). The authors found no unequivocal evidence of benefit for any single or multi-nutrient formulation post-diagnosis, excluding individuals with an established deficiency requiring treatment. Of the weak evidence presented, the strongest signals were for Vitamin E, Omega-3 fatty acids, and possibly for the "medical food" Fortasyn Connect (Souvenaid™). Further Souvenaid™ data published since that review would not appear to improve this assessment (Soininen 2020).

A narrative review of dietary interventions to slow cognitive decline (Nelson 2015) could not find any substantive evidence to support the general use of micronutrient or single-agent supplementation strategies.

In respect of whole diet interventions, dietary counselling advice to the care partners and general practitioners of people with dementia reduced the risk of malnutrition but was otherwise ineffective versus symptomatic outcomes (Vlachos 2019). One of the complexities is that dietary strategies probably need to change as the syndrome progresses, with brain-healthy diets targeting disease progression being potentially useful in early stages but weight loss and malnutrition becoming the main therapeutic targets later in the illness (Nelson 2015). Indeed, a recent opinion piece argues that there is a danger that attempts to encourage strict adherence to more prescriptive dietary statements for people concerned about dementia might backfire by raising the risk of under-nutrition (Yerstein 2020). Paying attention to swallowing safety and the encouragement of eating may be more effective than focussing on diet itself for some people.

A relevant network meta-analysis was not able to demonstrate any differential benefit of nutritional interventions in comparison with physical exercise, music therapy, or cognitive training, but was only calculated on the basis of four studies (Liang 2018).

However disappointing this may all seem, it must be accepted that research challenges are strongly stacked against identifying a signal for effectiveness post-diagnostic dietary interventions against the noise of everything else that affects cognitive decline at this relatively late stage of the neuropathological journey, especially over short time frames. However, the absence of evidence for an effect does not equate to evidence of absence of an effect, especially if broader goals such as improving general caloric intake are considered.

For example, increasing positive affect and pro-social experiences relating to food are worthy goals, but they will likely sit best within a multi-modal dementia intervention or a diet-based general health intervention that people with cognitive impairment might attend alongside peers, rather than constituting a stand-alone dementia intervention for a community dementia NGO. An example of such a multi-modal intervention with dietary effects of interest to Aotearoa New Zealand is the provision of day programmes for people with dementia at farms in the Netherlands, termed "Green Care Farms". This scheme has been shown to be associated with higher fluid and total energy intake (particularly carbohydrates and proteins) compared with standard day programme venues (De Bruin 2010).

Exercise

A number of meta-analyses have been conducted examining the effect of exercise programmes on outcomes for people with dementia. The literature is reasonably large and a range of outcomes are studied including cognitive outcomes of various kinds; functional abilities, for example with activities of daily living; quality of life; and physical fitness measures. The most recent meta-analysis (Pisani 2021) was able to identify seven RCTs over the previous decade that measured the effect of exercise on people with Alzheimer's dementia using the MMSE (with insufficient number using the ADAS-Cog to enable analysis). It estimated a respectable effect size of 0.46 but the confidence limits ran from 0.1 to 0.8 so although an effect is demonstrated, its clinical significance is difficult to ascertain. Notably, the estimated effect size was similar to that estimated for Donepezil in the same study.

The next-most recent meta-analysis (Jia 2019) was able to access Chinese scientific databases as well as Euro-American ones, giving it superior coverage. It found a statistically significant effect of exercise on cognition as measured by MMSE, and while the clinical significance of the standard mean difference of just over 1 point on this 30-point scale is debatable, all studies showed at least a trend for improvement and the effect is comparable with those of cognition enhancing medicines over similar time periods (Rountree 2009). Numbers were insufficient to be clear about dose effects and threshold effects (that is, whether more exercise is better than less and if so, whether this benefit ceases above a certain level of intensity) but there was a suggestion that these kinds of specifiers may exist.

A network meta-analysis (Liang 2018) compared physical interventions with other intervention types (dietary, music therapy, and cognitive training) and determined that there was a signal for a differential benefit of physical exercise on cognitive outcomes compared with these other modalities, however this was calculated on the basis of just four exercise studies.

Other meta-analyses have provided mixed results. Another Chinese group (Du 2018) meta-analysed a somewhat different collection of studies than Jia's group and estimated a significant and perhaps surprisingly large aggregated mean difference from exercise of 2.5 points on the MMSE. The most recent Cochrane Review (Forbes 2015) which looked at a more comprehensive group of older studies found no significant effect of exercise on cognitive outcomes, even when a study which did not exclude more cognitively impaired people was excluded from their analysis. The very first meta-analysis in this field (Heyn 2004) was particularly thorough and did demonstrate a fairly robust benefit in terms of cognitive outcomes, reporting this as an effect size of 0.57, but this analysis did not separate out MCI from dementia. They also demonstrated benefits across the whole range of outcomes outside of cognition.

The most recent systematic review (Nuzum 2020) concludes that there is sufficient evidence to conclude that physical activity, specifically aerobic exercise, can be linked with benefits for people living with dementia in functional abilities and psychological well-being, but perhaps not cognition itself (whereas the evidence for cognitive benefits in MCI were more convincing for these authors). It is noteworthy that a synthesis of systematic reviews of psychosocial interventions for people with dementia overall found evidence supporting exercise programmes (as opposed to most other types of intervention) consistently producing physical and cognitive benefits as well as for activities of daily living, adding that evidence appeared to be strongest for multicomponent exercise programmes of sufficient intensity (McDermott 2019). An earlier narrative review was cautiously positive but on the basis of very little data (Ahlskog 2011).

A specific exercise mode that has been studied with people living with dementia called “Multicomponent Training” combines aerobic, strength, postural, and balance exercises (Borges-Machado 2021). The intervention typically involves 30 minute guided sessions of moderate exercise intensity but the specific content varies widely, as might be expected. The studies included for analysis offered sessions twice or more per week, from a minimum of 4 to a maximum of 24 months, in a variety of settings from individual ‘coaching’ in private homes to group sessions in aged residential care. Six studies were able to be reviewed and the authors concluded that adherence was good (70-80%) and functioning measured by ADL scales improved, but cognitive and surprisingly even physical fitness measures were not shown to improve in meta-analysis, possibly because the study designs were too heterogenous, but no doubt also due to the same signal versus noise problem that bedevils all research aimed at slowing the progression of chronic diseases.

The Minds in Motion® initiative is a noteworthy programme developed within the Alzheimer Society of Ontario network. It is an 8-week program for people with mild to moderate dementia and their care partners which runs once a week for 2 hours per session, divided roughly 50:50 between a session of multicomponent exercise and a session of cognitive stimulation activities. Details can be accessed at: https://alzheimer.ca/on/en/help-support/programs-services/minds-in-motion and in an editorial discussion (Watson 2020). The pilot evaluation (Regan 2019) was positive in respect of physical functioning measures and well-being. Functional and cognitive outcomes were not measured.

The Seattle Protocols are a series of structured interventions that trained staff can deliver in a person’s home for people with dementia and their care partners. While they were originally developed to help treat low mood in the context of dementia, they have expanded and their exercise component has been particularly studied. The approach matches a problem-solving approach with motivational enhancement strategies to encourage exercise to become a habit. A group version has also been developed. A narrative summary of some of the supporting literature (Teri 2008) concludes that the protocols are acceptable to participants and lead to sustained improvements in exercise engagement and improved mood over two years, as well as improved sleep. It may be that aspects of this kind of approach are worth considering in respect of exercise programmes, in particular the focus on skill building for the person with dementia / care partner dyad.

Exercise emerges from these literature reviews as a pluripotent and acceptable intervention in terms of modifying dementia progression, with benefits in respect of well-being, mood, activities of daily living and physical functioning, and less certain but plausible benefits on cognitive outcomes. Exercise programmes would also seem readily able to be included as part of multi-modal interventions.

Cognitive treatment strategies

A range of specific cognitive treatment strategies have been applied to dementia. The most prominent of these are Cognitive Stimulation treatments, which typically involve a suite of cognitive training methods made available without individualisation, and sometimes without a trained therapist, to individuals or to groups of people with dementia, to improve cognitive and daily functioning in a general way. This covers everything from cognitive training apps available for download through to manualised Cognitive Stimulation Therapy (CST). In contrast, Cognitive Remediation is an individually-targeted approach that identifies a person's specific areas of cognitive impairment and seeks to apply tailored cognitive training to improve these deficits. This treatment mode is sometimes called "Cognitive Training" or "Retraining". Cognitive Rehabilitation is also individualised but focusses on the functional goals that a person wishes to achieve, and adopts work-arounds and aids in addition to boosting specific cognitive skills. All three approaches exist on a continuum and there is considerable overlap in practice.

Reminiscence therapy can be considered to be a type of cognitive stimulation therapy but since it has a longer history than others in the class, in particular as a person-centred care intervention rather than as a 'treatment' for cognitive impairment, it is considered separately in the "Other Specific Therapies" section.

The most recently published review of Cognitive Stimulation, perhaps controversially including Reality Orientation treatment studies as the bulk of the randomised controlled trials reviewed, was able to conclude that there was good evidence for benefits on cognitive function but less certainty regarding benefits for depression and quality of life (Wong 2021). Using a more agreed definition of Cognitive Stimulation, the other most recent review was able to meta-analyse 14 studies and not only concluded that there was a moderate benefit in terms of cognitive outcomes (mean difference of 2.21 on the ADAS-Cog and 1.41 on the MMSE) but also that there was a quality-of-life benefit for the people with dementia who participated (with a standard mean difference of 2.05 compared to controls, Kim 2017). The authors of a review of reviews of psychosocial interventions for people with dementia overall specifically mention group cognitive stimulation studies as consistently showing benefits for cognition, social interaction, and quality of life (McDermott 2019). A prior Cochrane Collaboration review also found benefits in relation to cognitive outcomes (whether cognition enhancing medications were also taken or not), highlighting less robust but favourable data in respect of quality of life and well-being measures (Woods 2012).

The formal "CST" programme is the main evidence-based cognitive stimulation option available in Aotearoa New Zealand. This treatment was originally prototyped in Paris by Breuil and colleagues (Breuil 1994) and has since been championed via a global network centred on the University College London. The process of development has been relatively thorough (as documented by Rai 2018). CST comprises 14 twice-weekly structured and themed group sessions lasting about 45min offered over 7 weeks. The most recent systematic review (Lobbia 2019) was able to review 12 studies (Including 8 RCTs and 4 cohort studies) and found that there is moderate evidence for improvements in general cognitive function, language skills, and improved quality of life for people with mild to moderate dementia.

Concern that benefits may drop off after treatment ends have resulted in development of “Maintenance CST” which has been shown to lead to additional benefits in quality of life but not in cognition over 6 months (Orrell 2018). Although cognitive outcomes are clearly important, benefits in respect of engendering hope and improving quality of life are also very important, especially in the early period post-diagnosis. A very recent review of studies on care partner outcomes has demonstrated positive effects on emotional interactions and communication in the care partner: person with dementia dyad (Lauritzen 2022). A study of participants’ experience of CST highlights the social benefits of CST as well as the potential that group processes may be a key mediator of the programme’s benefits (Orfanos 2021). Nevertheless, randomised controlled trials examining individualised CST programmes offered on-to-one have shown mixed results but may yet prove to be effective (most recently, Gibbor 2021).

Following the NICE recommendation that all people with dementia in the UK should have access to CST on the basis of its cost effectiveness, acceptability, and clinical effectiveness, it has become widely available in Britain, however the authors of a mixed methods descriptive study of British practice found “there is significant variability in how CST is used in clinical practice with many trusts not adhering to the evidence base" (Holden 2021). Naturally, it is unclear if non-standard versions of CST are as effective as the standard version. A study of the facilitators and barriers to the roll-out of CST in England did not arrive at firm conclusions as to why uptake was not universal but did wonder if stigmatising attitudes to dementia and to non-pharmacological treatments might be at play (Dickinson 2017). The Scottish Guidelines also recommend CST as part of standard care.

Three economic evaluations of the cost-effectiveness of group CST have been published, briefly reviewed in the fourth such paper, which sought to examine cost-effectiveness for Maintenance CST (D'Amico 2015). The authors assert that CST has been shown to be cost-effective in all three group studies and that maintenance treatment is also cost-effective in terms of quality of life (using QALYs), however the data were not convincing over six months in terms of cognitive outcomes.

CST has been recommended in Aotearoa New Zealand by Te Pou following the formal development of a national version with the assistance of UCL (Cheung 2014). A kaupapa Māori version, "Rongoā Mate Wareware" has also been developed and trialled in some North Island sites.

CST is not universally available across all health districts in Aotearoa New Zealand and access within those health jurisdictions is not wide, but echoing the UK experience, some additional sites offer cognitive stimulation programmes that are locally developed and aligned with the principles of CST rather than following the programme-proper. The main risk from this idiosyncratic approach is that service users cannot be assured that they are being offered a treatment that has been proven to be effective against the clinical targets identified in the CST trials.

Cognitive remediation approaches have been meta-analysed by the Cochrane collaboration under the title "Cognitive Training" in respect of people with mild to moderate dementia (Bahar-Fuchs A 2019). Although significant methodological limitations and marked study heterogeneity were present, the authors conclude that there is moderate-strength evidence to support a small to moderate benefit on global cognition and on verbal fluency measures, and these persisted up to a year post-treatment. However, this could not be shown to translate into improved functioning or improved quality of life, and when directly compared with other treatments such as cognitive stimulation, differential benefits were not demonstrated.

Cognitive rehabilitation has been studied in the context of dementia by two groups (a Cochrane review has been planned but not published). It is an approach taken by at least one day programme in Aotearoa New Zealand, where it has been described as being acceptable and helpful (Moebs 2017). In the UK, the GREAT group developed a 10-week protocol of 1hr sessions between a clinician (mainly occupational therapists) and individuals with dementia in their own homes, followed by four maintenance sessions over six months. The aims were to negotiate shared goals relating to everyday activities and to develop rehabilitative strategies in respect of those goals, for example, to be able to remember the names of close family members. The study was able to demonstrate that goal attainment was achieved well but secondary benefits such as generalised improvement in general activities of daily living, quality of life, mood, and cognitive outcomes could not be shown (Clare 2019). Both people with dementia and their care partners valued the programme, especially the individualised nature of the goal-setting and qualities of the therapists, but concerns about how any improvements might one day still be eroded by the underlying condition could pose a barrier to engagement (Warmouth 2022).

Notably, a German programme, CORDIAL, consisted of 12 weekly 1 hr sessions covering a variety of skills and techniques such as developing daily routines but was not individualised except insofar as therapists did deliver it in people’s homes. This could not demonstrate any benefits on functional, cognitive, or quality of life outcomes (Kurz 2012). Rehabilitative approaches such as these are able to be viewed as a subset of the broader application of occupational therapy to people with dementia. In this light, there has been one review of occupational therapy interventions per se (Bennett 2019), all of which were of individualised home-based interventions. The authors concluded that benefits could be demonstrated in respect of activities (and instrumental activities) of daily living, to so-called behavioural and psychological symptoms of dementia, and to measures of care partner burden, but the reviewed studies' designs did not enable collection of high quality data from a qualitative perspective.

One large study, ETNA3 has attempted to compare results from a cognitive stimulation-like therapy (reminiscence therapy), cognitive training, and cognitive rehabilitation for people with mild dementia (Amieva 2016). It was a moderately large (n=653) French multicentre, randomised, controlled, parallel-group trial with two-year follow-up from the initiation of the interventions. Psychologists were trained to offer group cognitive training, group reminiscence therapy, or individual rehabilitative programmes. Each condition comprised 12 weekly sessions followed by six-weekly boosters until the study ended. No differences between the control treatment as usual condition and the two group treatments were identified in the primary measure of progression to moderately severe dementia or to any secondary endpoint, but individualised cognitive remediation was associated with some improved secondary endpoints: functional abilities measured by general scales (such as the Disablement Assessment for Dementia) and a six-month delay in entry to aged residential care.

Out of all these cognitive treatments studies, cognitive stimulation therapies, CST in particular, are highlighted as having the strongest evidence base in respect of cognitive outcomes, and they also show benefits for quality of life and communication skills. Part of the ‘magic’ seems to be the group-based format these groups typically follow, however not all studies support this conclusion, including some of the largest trials of non-pharmacological treatments ever run in the context of dementia. Notably, participants with dementia and their care partners typically value cognitive interventions highly no matter what type of treatment they offer.

Summary: Modifying dementia progression

- Evidence to support community-based interventions using diet to modify dementia progression is not strong.
- The effectiveness of physical exercise interventions and cognitive stimulation programmes delivered in group settings is supported by the literature.
- There are hints that conjoint programmes may be feasible and acceptable (as in Minds in Motion®), however, this kind of programme does not meet the model purity required to optimise the chance of realising the benefits of the cognitive stimulation component.
- On this reading of the literature, a formal CST offering is the most supported disease modifying treatment modality indicated for inclusion in community post-diagnostic services in Aotearoa New Zealand.

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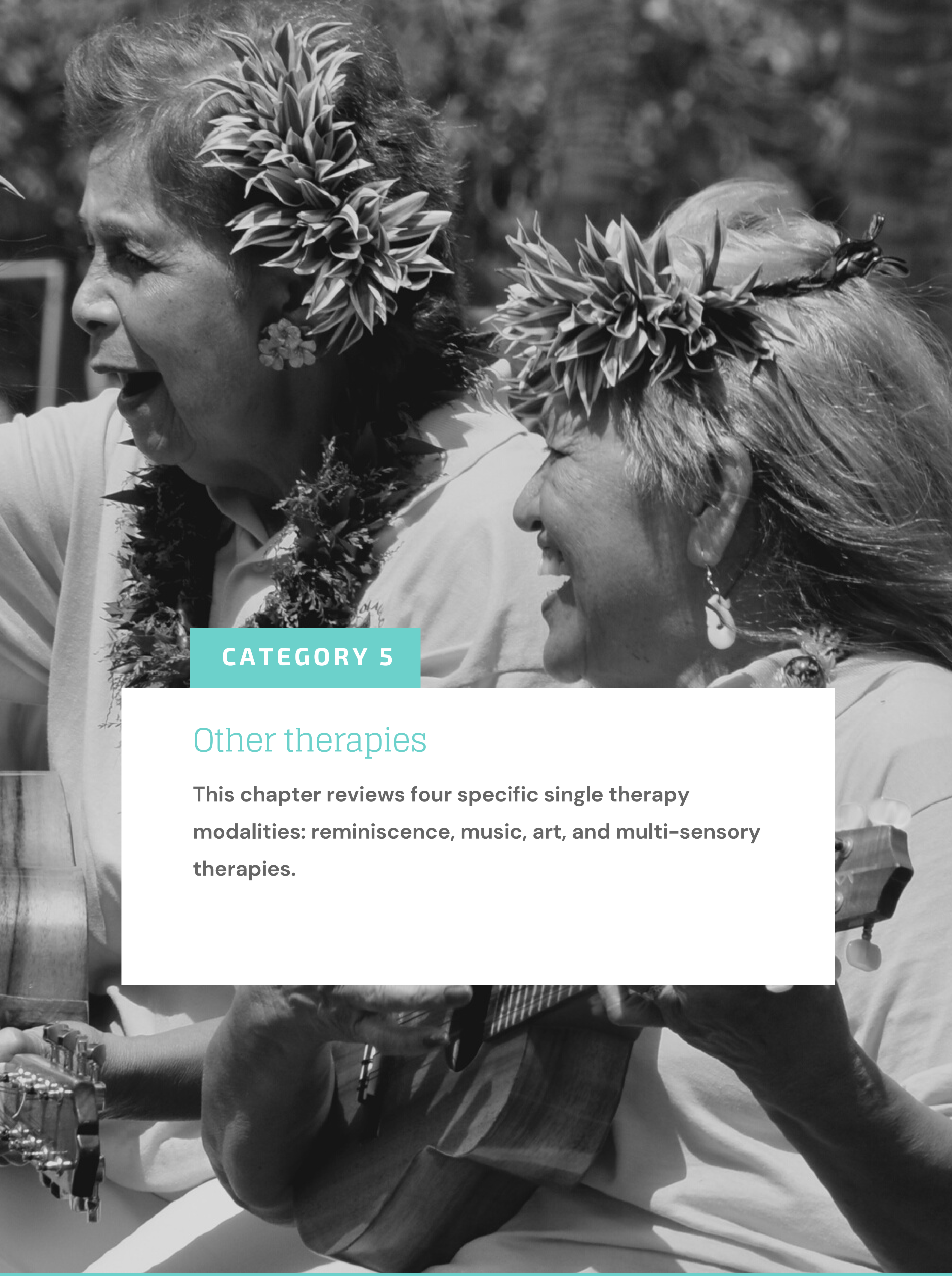

CATEGORY 5

Other therapies

This chapter reviews four specific single therapy modalities: reminiscence, music, art, and multi-sensory therapies.

Other therapies

Many specific therapeutic interventions are outlined in the literature, so the decision as to which modes would be included in this section of the review was guided by the size of the evidence base in tandem with knowledge about what is currently offered in Aotearoa New Zealand settings. The specific modes reviewed are Reminiscence Therapy (including Life Story work), Music Therapy, Art Therapy, and Multi-sensory Therapy (including Snoezelen).

Reminiscence

A range of therapeutic approaches have been gathered under this grouping. They range from simple autobiographical storytelling, via more reflective evaluative approaches to personal memories, to more extensive psychotherapeutic work based on such stories, including re-framing and positive meaning-making. However, all levels of reminiscence lend themselves to the creation of a "Life Story" record or other physical repositories of the work done, such as creating a Memory Box (Macleod 2021). This heterogeneity makes systematically analysing outcomes from these approaches challenging.

The most recent meta-analysis relevant to this therapy type sought to sample studies covering a broad range of person-centred approaches, notably finding that the evidence supporting reminiscence therapy was the strongest of all those surveyed, with pooled data indicating net benefits on behavioural and psychological symptoms and on cognitive function (Lee 2022).

The most recent systematic reviews are both small and problematic in terms of their methods and reporting. One review further limited itself by focussing solely on studies with people with dementia of Alzheimer type (Cuevas 2020). These authors noted that this therapy modality can produce benefits in cognitive, mood, quality of life, and daily functioning; and posit that it is best when the reminiscence is highly personalised by use of personal photographs and other triggers with strong personal meaning to individuals. A second review restricted itself to the small field of data in respect of people with mild to moderate dementia in aged residential care (Thomas 2021). This review found signals for improved quality of life but few other outcomes.

A more exacting and rigorous systematic review of the broad field of psychosocial interventions for people with moderate to severe dementia highlighted the quality of a single study of reminiscence therapy (Hui 2021 referring to Azcurra 2012). This stood out to the reviewers in terms of the strength of its evidence for a benefit to quality of life for this more impaired group.

The most rigorous treatment is from the Cochrane Collaboration, in which the authors

(Woods 2018) were able to meta-analyse 16 studies to show a likely benefit on measures of communication functioning and on cognition. Their ability to make general conclusions was limited because the effect sizes reported were small and inconsistent and the studies themselves too heterogenous. The authors did, however, note that more individualised approaches seem to be associated with improved measures of cognition and mood, and group approaches were associated with communication skills improvements.

A systematic review of studies of digital aids in reminiscence therapy highlighted how technology can be used to mitigate motor difficulties for some participants, how it can enable multi-sensory prompts (typically coupling a visual image with audio), and how it allows therapists to access a wider range of materials that are of particular relevance for individuals, as well as enabling them to deliver the therapy remotely (Lazar 2014).

A particular method for encapsulating reminiscence therapy is the "Life Story" approach, which has become a named therapy modality in itself even though the term can be used for a wide range of actual methods. A systematic review of this approach (Elfrink 2018) highlights small sample sizes but can still report on five controlled trials which between them demonstrated significant improvements in measures of autobiographical memory, mood, quality of life, communication skills, relationship with (family) care partners, and benefits for the aged care staff involved. These findings were consistent with the findings of the larger number of descriptive studies reviewed.

An important meta-outcome is the enhancement of person-centred care for the person with dementia by their formal and informal care partners when Reminiscence Therapies are utilised. Whilst there is an intrinsic bias toward more person-centred care in the other cognitive therapeutic approaches (least for remediation / training, medium for stimulation, and most for rehabilitation), Life Story versions of reminiscence therapy are inseparable from the co-development of a deeper understanding of a person's own values and core narratives with people who are living with a dementia. This is a powerful argument in favour of their use. Additionally, in the Aotearoa New Zealand context where most people currently living with dementia are likely to have been born in this country, near-ubiquitous exposure to the “This Is Your Life” television series (from 1984 to 2011) also establishes an important cultural bridge with those versions of the Life Story model that result in the compilation of a written or pictorial record.

Another important meta-outcome is that Life Story work would also be expected to result in improved personalisation of best-practice medicalised care, particularly in hospital, aged residential care, and day programme settings where staff do not always have a deep knowledge of a person's individual preferences and experiences. These meta-outcomes are not well-measured, if they are considered at all, within the published literature.

An important question that remains unclear is whether the benefits to the person with dementia from reminiscence therapy are more evident once the dementia syndrome has progressed so that it is difficult for the person to hold or express their narrative without assistance, or if the benefits from Life Story work are realised more completely earlier in their dementia journey when they can participate more fully in the process.

Music

Using the obvious definition of being "the use of music as a therapy", whether this be by listening to music, making music, or studying / reflecting on it, the most recent review of music-based therapies employed to treat people with dementia identified 8 papers able to be subjected to full review because they formally evaluated cognitive function – 13 others were of high quality but could not shed light on cognition so were ignored (Moreno-Morales 2020). A small effect size was demonstrated for cognitive function (0.23) but the effect on quality of life was somewhat stronger (0.36). Persisting improvements in these indices and on depression after six months were not able to be shown.

The most recent iteration of the Cochrane Collaboration's systematic review took a broader approach in respect of outcomes and was able to include 22 studies in at least one analysis (Van Der Steen 2018). Interestingly, all these studies were conducted in aged residential care settings or hospitals. Analysis of immediate post-treatment results enabled the authors to conclude that there were benefits on depression and overall measures of behaviours that were identified as challenging (but not the specific domains of agitation or aggression), with less robust findings in favour of benefits for anxiety, emotional well-being, and quality of life. Data were not robust enough to make comments on the durability of these gains.

A review of reviews solely examining non-pharmacological treatments for apathy highlighted the benefits of music therapy and further posited that there is a particular place for being enabled to passively listen to music rather than be required to participate in music-making (Cai 2020).

In Aotearoa New Zealand, music therapists are relatively rare but group music sessions such as dementia choirs (or for broader neurological disorder groups) are becoming more common. Musical elements are also used in many therapeutic interventions, from informal inclusion in care situations such as singing together during showering to more formal interventions such as enabling people to listen to personalised playlists via headphones as a targeted treatment to help manage anxiety, stimulate motivated behaviour, or more importantly, to support and enhance personhood. Any kaupapa Māori approach to a community programme for mate wareware would be likely to incorporate waiata as a key element because of their high cultural significance for the process of engagement between participants as well as their power to support individual mauri and collective mana and to bring joy.

Art

The most recent review of this group of interventions identified 17 studies that utilised either art-making (typically painting), art appreciation, or both as therapeutic modalities (Emblad 2021). Most participants lived at home but some were living in aged residential care. The authors took an unusual approach to comparing outcomes across the literature – first identifying the three main categories of outcome studied (quality of life, behavioural and psychological symptoms, and well-being) and then calculating the proportion of studies that found significant benefits for each category. This idiosyncratic reporting choice makes conclusions difficult to draw but the main finding is clearly that 16/17 studies found a benefit to quality of life at the conclusion of the intervention.

The most recent Cochrane review (Deshmukh 2018) is based on only two studies in which the comparator groups were not placebos. Neither found differential changes in cognitive or any other outcomes but the total numbers involved were small in any case.

An earlier systematic review posits that the restricted methods employed by the evidence-based medicine movement predicate against research that can demonstrate the potential for art therapies to enrich peoples' lives, and concludes that until studies can investigate subjective well-being more fully, art therapy studies will continue to fall short of being able to evaluate its true effects (Beard 2011).

Multi-sensory

A range of sensory stimulation therapies have been trialled in the context of dementia, seeking to provide pleasant experiences in one or more senses, either in a 'pure' modality such as from an undifferentiated coloured light projector or specifically in relation to emotional or autobiographical contexts. "Snoezelen" is the most frequently studied approach and is multisensory, typically presenting low-intensity sensory options in the domains of sight, sound, touch, and smell in a designated room, in which individuals with dementia can choose what they wish to interact with.

Another named programme of note is the Sonas® approach, developed in Ireland. Licensed practitioners facilitate individual or group sessions based around pre-recorded content to stimulate all five senses with gentle exercise, music, and cognitive exercises. Although this is clearly multi-modal, the core underpinning model is based on a multi-sensory approach. A number of studies have been published (briefly reviewed in Goyal 2021) but the chief population studied seems to be people with moderate to severe dementia living in aged residential care so this approach is not likely to be applicable to community dementia NGO services.

The most recent systematic review of sensory stimulation programmes (Pinto 2020) concluded that there was only weak evidence to support treatment effects, with conflicting results possibly best for Snoezelen treatment in respect of improved behavioural and psychological symptoms, and finding that these approaches were most often utilised for people with more significant dementia. Another recent review with greater coverage of the Spanish and Portuguese literature found similarly disappointing results but again found a stronger signal for effectiveness in reducing agitation and, to a lesser extent, anxiety (Silva 2019). A narrative review of reviews focussing solely on apathy concluded that multisensory therapies were effective for this particular symptom (Cai 2020).

Summary:
Other therapies

- Overall, there is reasonable support from the literature that a reminiscence therapy model could be considered to be a good choice for community services in terms of its benefits to the person. This may be particularly useful if it produces a Life Story record of some kind that might result in lasting benefits, for example for the care services that work with that person in future. However, the evidence is weaker than for some other interventions considered elsewhere in this review such as exercise and navigation.
- In respect of music therapies, while there is reasonable evidence for enhanced quality of life at the time that the musical intervention is occurring, there is no strong signal from the literature that these should be considered essential components of community services for people with dementia. However, there are reasons to consider therapeutic musical

activities being incorporated into community interventions where there is a cultural or practical ‘fit’.

- **In terms of art therapies, there is insufficient evidence from the available literature to support art therapy approaches being an essential component of community services for people with dementia, however they may be a useful adjunct alongside other more established elements such as reminiscence therapy or cognitive stimulation.**
- **There is insufficient support for the use of multisensory therapies such as Snoezelen within the core menu of NGO community services for people with dementia, particularly since the majority of the communities they serve will be experiencing mild to moderate dementia rather than more severe illness.**

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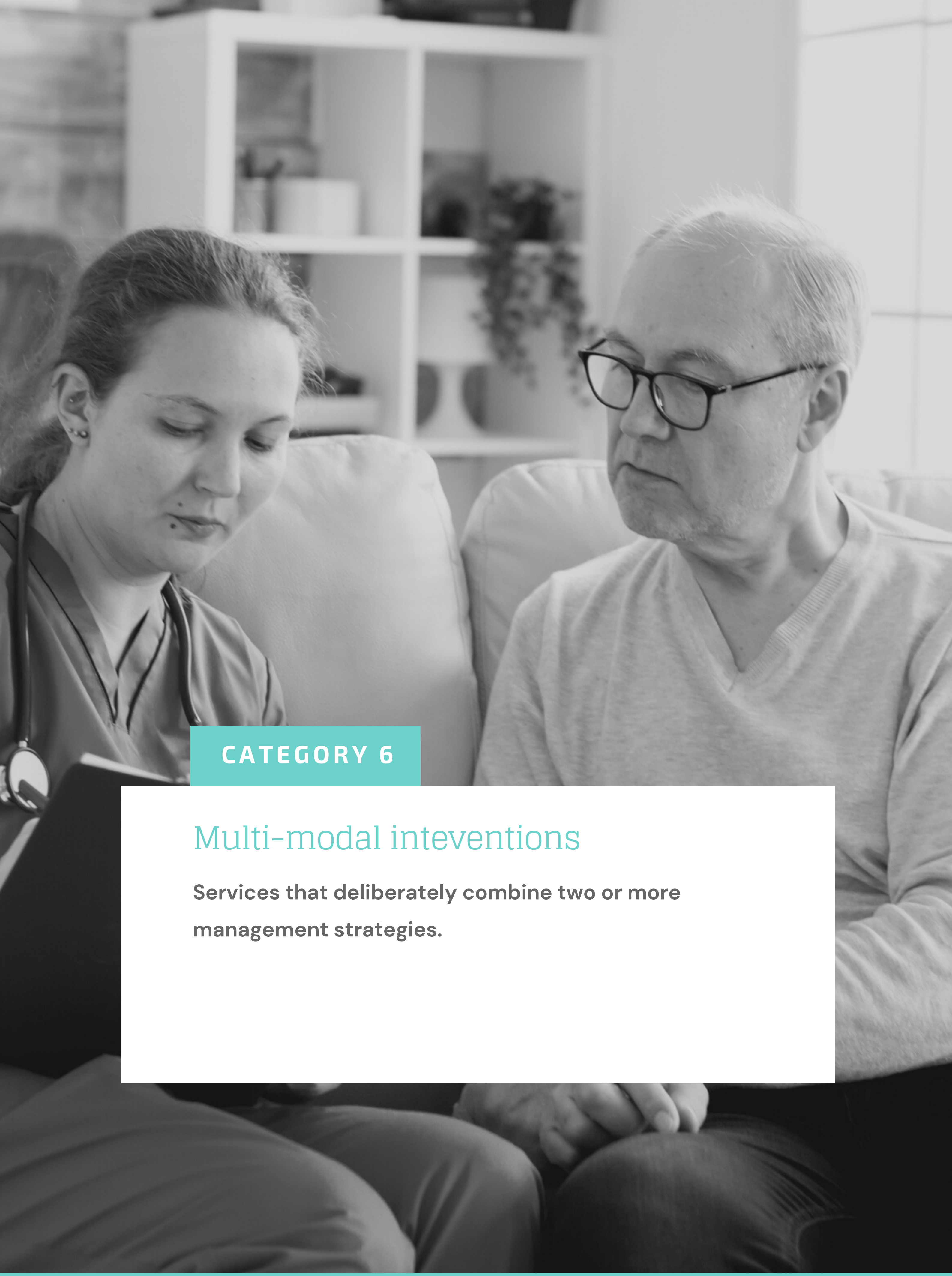

CATEGORY 6

Multi-modal inteventions

Services that deliberately combine two or more management strategies.

Multi-modal

It is impossible to imagine any stand-alone dementia service programme that does not include mixed elements to some extent. For example, the process of cognitive remediation will always meet some social contact goals, and the process of providing psychoeducation in a group will always meet some emotional support and service navigation goals.

It is also impossible to imagine a community dementia NGO offering only one programme. Typically, several are offered in sequence or in tandem to people with dementia and their care partners. Some of these programmes designed with one primary therapeutic goal or mode of providing treatment in mind (for example, a psychoeducation intervention followed by a cognitive stimulation programme); taken together, comprehensive coverage is achieved.

Some programmes, such as the Minds in Motion® course, deliberately set about to combine two or more management strategies. Aotearoa New Zealand data have provided support for the concept of such multi-modal strategies, with one detailed investigation of dementia dyads post-diagnosis finding that quality of life for both parties improved most when information and support were combined (Gallrach 2010). This section attempts to review such multi-modal interventions provided by community services but does not include reviews and studies of multifactorial individualised care plans offered by Memory Clinics or primary care settings. It also reviews "case management" as an intervention because this is an intrinsically multi-modal intervention, albeit one delivered to people with dementia and their care partners by a named individual.

Multi-modal programmes

The range of multi-modal intervention studies in the context of dementia is so small that all the published reviews exist as subsections of larger reviews of psychosocial interventions, and not all of those report multi-modal data relevant to this literature review in a helpful way. The most helpful paper analyses four prior reviews of psychosocial treatments that treated multi-modal interventions separately from single-mode programmes (Dickinson 2017). The results considered as a group were encouraging, with most studies demonstrating benefits ranging from care partner depressive symptom improvement and increased social support (for example, Elvish 2013) to delayed entry into aged residential care for the person with dementia. The evidence to support this latter effect was surprisingly good with meta-analyses in two reviews both finding in the order of one third less risk of entry into care (Olazarán 2010 & Pinquart 2006) for multimodal interventions. It is notable that the Mittleman / NYUCI programme's outcomes research featured prominently in both reviews (discussed in the Personal and Emotional Support section of this review).

The signal is that to be efficacious, interventions needed to be highly structured programmes including psychoeducation, support, and counselling (Dickinson 2017). This was reinforced by an Australian review of a broad range of interventions for co-residing care partners which concluded that:

> **Multimodal interventions appeared to be particularly beneficial for co-residing care partners, typically including combinations of counselling, support, education, stress and mood management, and telephone support (Abrahams 2018).**

Another group sought to meta-analyse six studies covering a range of multi-component care partner interventions. They found a robust treatment effect for care partner depression, with a seventh study that could not be meta-analysed also showing this benefit (Teahan 2020). An earlier systematic review concluded that the six studies of multi-modal interventions they identified all found significant benefits for care partner well-being, primarily reduced depression and increased social support (Elvish 2013).

Finally, an interesting review sought to meta-analyse studies of multi-component interventions to determine if there was an advantage for dyadic interventions versus those solely for the care-partner. It could not show any significant differences in outcomes across depression, quality of life, carer stress, and behavioural and psychological symptoms of dementia (Laver 2017).

No subsequent reviews were identified that covered the kinds of interventions that people with dementia living in the community might reasonably receive from a community dementia service provider. A possible exception is a Portuguese review which found modest evidence for an effect for mixed exercise and cognitive training programmes on cognitive outcomes (Lima Neta 2020), extending the positive findings of the Minds in Motion® pilot on physical and well-being measures (discussed in the Exercise component of the Modifying Dementia Progression section of this review). If it is accepted that 'pure' programmes are neither possible nor, perhaps desirable, and given the potential for more efficient use of scarce resources, these relatively scant but positive findings should encourage community service providers to purposefully consider providing carefully structured multi-modal programmes.

A specific multi-component programme focusing primarily on care partners that warrants closer examination is variously known in its different iterations as the Prince Henry Hospital (or Sydney) Caregivers' Training Programme and the Going to Stay at Home Programme. The original version (Brodaty 1997) was a ten-day residential course for cohorts of people with dementia and their care partners, run out of a psychogeriatric inpatient unit in a teaching hospital. Care partners received psycho-education, skills training, and low-level psychotherapeutic group interventions and the people with dementia received therapeutic sessions (such as reminiscence therapy) interspersed with tailored and group occupational activities. Both groups were encouraged to form relationships with each other and to enjoy the experience as a whole. Once the course was over, follow-up included a schedule of decreasingly frequent one-to-one phone reviews as well as occasional face-to-face group meetings. It was an intensive intervention. A revised intervention (Gresham 2018) reduced the residential experience to five full days, situated it in an aged residential care unit made up of separate cottages, provided less in the way of specific therapies as opposed to therapeutic activities for the people with dementia, but included similar planned follow-up. The content of the interventions for both care partners and people with dementia is provided by the authors.

The first iteration has been reported in several papers, with the most impressive evidence coming from an RCT with follow-up extending a minimum of 6.5 years post-programme (Brodaty 1997). This study was able to demonstrate a statistically significant delay in entry into aged residential care for the intervention dyads were followed-up. The benefits were also evident earlier, at three and five years, with three-year cost effectiveness also being clearly demonstrated (Brodaty 1991).

The programme's more recent revision study (Gresham 2018) used a pre- and post-intervention design to show a persistent decrease in behaviours that the care partners found challenging (measured by the NPI) as well as improved care partner ratings of their unmet needs. Unfortunately, a thoughtful attempt to construct a control group through a comparison with users of routine residential respite care is too open to bias to confidently interpret the observed differences in entry into permanent aged care. In addition, the intervention is too different from its parent programme for the older results to be imputed to the newer programme. Nonetheless, this is a very interesting model because it is a short, sharp intervention in the face of a very chronic condition, because it adds to the weight of literature showing that caregiver training and support can make a significant difference, and because it gave rise to a programme that attracted state government funding for wider adoption in New South Wales.

Case management

Case management in this context can be defined as an episode of individualised contact between a person with dementia, their family members, and other support people with a health professional or peer support worker to organise and coordinate care (peer workers are usually people with lived experience as a family member of a person with dementia). Case management has been so strongly recommended by some authors as an ideal vehicle for providing post-diagnostic services for people with dementia that it formed the backbone of the models established by the Scottish National Clinical Guideline on the management of patients with dementia (Scottish Intercollegiate Guidelines Network 2006) and the National Dementia Strategy in operation in England and Wales (Department of Health (UK) 2009). The recent consensus statement from the European "Actifcare" project advises that people with dementia and their family or other care partners should have permanent access to a named contact person who is trained in dementia and person-centred care, has sound knowledge of available dementia services, and a clear relationship with the local dementia care pathway (Røsvik 2021).

A core rationale for these repeated recommendations is that the needs of people post-diagnosis are so individual that a flexible, complex and personalised response is required to meet them: these are more or less the defining qualities of case management (Bunn 2012).

Following the second iteration of Scotland's National Dementia Strategy in 2013, post-diagnostic services were expected to assign a "Linkworker" to every person with dementia with the task of working alongside them and their family / support people for at least one year to achieve what have been called the "Five Pillars" of Alzheimer Scotland's recommended model of care:

- Coming to terms with the diagnosis, understanding the illness, and (self-)managing symptoms,
- Obtaining peer support,
- Enhancing / maintaining community connections and social networks,
- Developing shared care and advanced care plans, and
- Planning for future supported decision-making via EPAs.

Sometimes these Linkworkers were clinicians in older persons mental health teams, particularly community psychiatric nurses, and sometimes they were connected to Alzheimer Scotland. Three different services in Glasgow were evaluated in 2014/15 (Levin 2018), with the authors finding greater than expected variation in service provision methods despite the shared underlying model of care outline. This included variation in what clinicians were deployed and what documentation was produced, even within single teams. The different appropriateness and achievability of each of the 'Five Pillars' was highlighted, mainly depending on the personal views and characteristics of the people being served and upon the stage of dementia the person was living with. Outcomes other than 'pillar attainment' were not formally measured and their attainment was not able to be robustly demonstrated robustly. The authors recommended that a standardised and detailed underpinning service provision framework needed to be enunciated, and the Linkworker function passed fully to Alzheimer Scotland (in Glasgow at least). Another Scottish study analysed another case worker-based '5 Pillars' pilot and found that the approach increased independence, motivation, and self-confidence of the participants with dementia (Kelly 2016).

Case management was vested in the concept of "Dementia Advisers" in England and Wales as part of their Dementia Services Strategy (Department of Health 2007). Again, this concept was applied inconsistently in terms of access, form, and function, with the roles taken up by health professionals called "Dementia Advisers" in some NHS Trusts and by "Admiral Nurses" under the NGO umbrella of Dementia UK in others, and in still others by both or neither of these clinical functions. The roles themselves vary greatly depending on local practices and demands but can include psychoeducation, workforce training, and provision of personal and emotional support, but they do typically include the provision of tailored service navigation assistance for people with dementia and their families (Bunn 2016). A qualitative programme evaluation based on demonstration sites concludes that the role clearly filled a perceived need in the post-diagnostic period because no services had previously been providing tailored psychoeducation, service navigation, personal support, and routes to accessing peer and general social supports; and that the Dementia Adviser system could be effective to fulfil these needs. A multi-modal service model was recommended, and the demonstration sites were believed by participants to be cost-effective, mainly by reducing demand for publicly-funded health services because dementia care partners avoided 'breakdown' as a result of better awareness of services and due to increased supportive peer relationships (Clarke 2013). Another reviewer notes that UK service users certainly value Admiral Nursing services and that the strongest signal for benefit is for reduced care partner depression (Bunn 2016). An economic evaluation concluded that Admiral Nursing does not seem to be measurably more expensive than 'treatment as usual' (Longo 2018).

An evaluation of the Irish service highlighted satisfaction with dementia advisers but noted that the delivery of value was dependent on the degree to which the advisors had functional relationships with the various stakeholders and service providers in each region (Coffey 2018).

A Cochrane Collaboration review of case management (Reilly 2015) was able to meta-analyse 13 randomised controlled trials involving nearly 10,000 participants with dementia. Heterogeneity of interventions and research methods challenged the reviewers and there was conflicting evidence for reduced entry into aged residential care (the literature analysed yielded reduced institutionalisation at 6 months follow-up (OR 0.82) and at 18 months (OR a robust 0.25) but no significant differences at 10-12 months or at 24 months). They also calculated reduced overall health costs over follow-up periods of up to a year and a half (in the order of $NZD 360 per annum) but there is insufficient evidence beyond that and the precision of these estimates was low. Evidence for positive clinical outcomes was uncertain.

A further model from the northeast of Germany called "Dementia Care Management" is of particular note because a thorough economic evaluation was built into the trial, and it demonstrates that case management interventions are best viewed as multi-modal interventions. Dementia nurses responded to GP referrals to provide comprehensive home-based service navigation, case management, and some direct therapeutic interventions to the people with dementia and, if available, their care partners based on algorithm-driven recommendations arising from standardised assessments (Michalowsky 2019). Compared with usual primary care, this approach delivered reduced costs of around $NZD900 over two years, largely because of delayed entry into aged residential care and reduced hospitalisations, with slightly improved quality of life (0.01-0.14 QALYs). Its value for this report is that it supports the broader contention that this kind of individualised intervention approach can deliver tangible economic gains, and because it was able to show that the benefits were even greater for people living alone with dementia, a perhaps surprising finding given the focus in some interventions on the co-residing care partner.

Summary: Multi-modal

- If it is accepted that ‘pure’ mode programmes are neither possible nor, perhaps, desirable; and given the potential for more economic use of scarce resources; these relatively scant but positive findings should encourage community service providers to purposefully consider providing carefully structured multi-modal programmes.
- Case management is revealed by these reviews to be valued by the people receiving it and likely to result in reduced entry into aged residential care in a cost-effective manner, and it also seems likely to benefit from having an explicit underlying set of clinical aims, if not agreed methods.
- By design, case management is an individualised approach, therefore the exact needs being met and the means by which the most appropriate services and interventions are brought to bear will vary widely. This is perhaps why research trials have struggled to identify group benefits on individual domains such as care partner distress or well-being for the person with dementia.
- Given the protean nature of the needs of people with dementia and their families and other care partners, the strength of the argument for case management becoming an

intrinsic part of what is available for people following a diagnosis of dementia will be affected by the complexity of the range of possible helping services or interventions. In Aotearoa New Zealand, the landscape is complex because there is often a broad range of both dementia-specific and general helping services provided by the health and social services sectors, by religious and civic organisations, NGOs, businesses, primary care, and secondary care. Therefore, case management would seem to be even more indicated as an essential component of any post-diagnostic care programme in our context.

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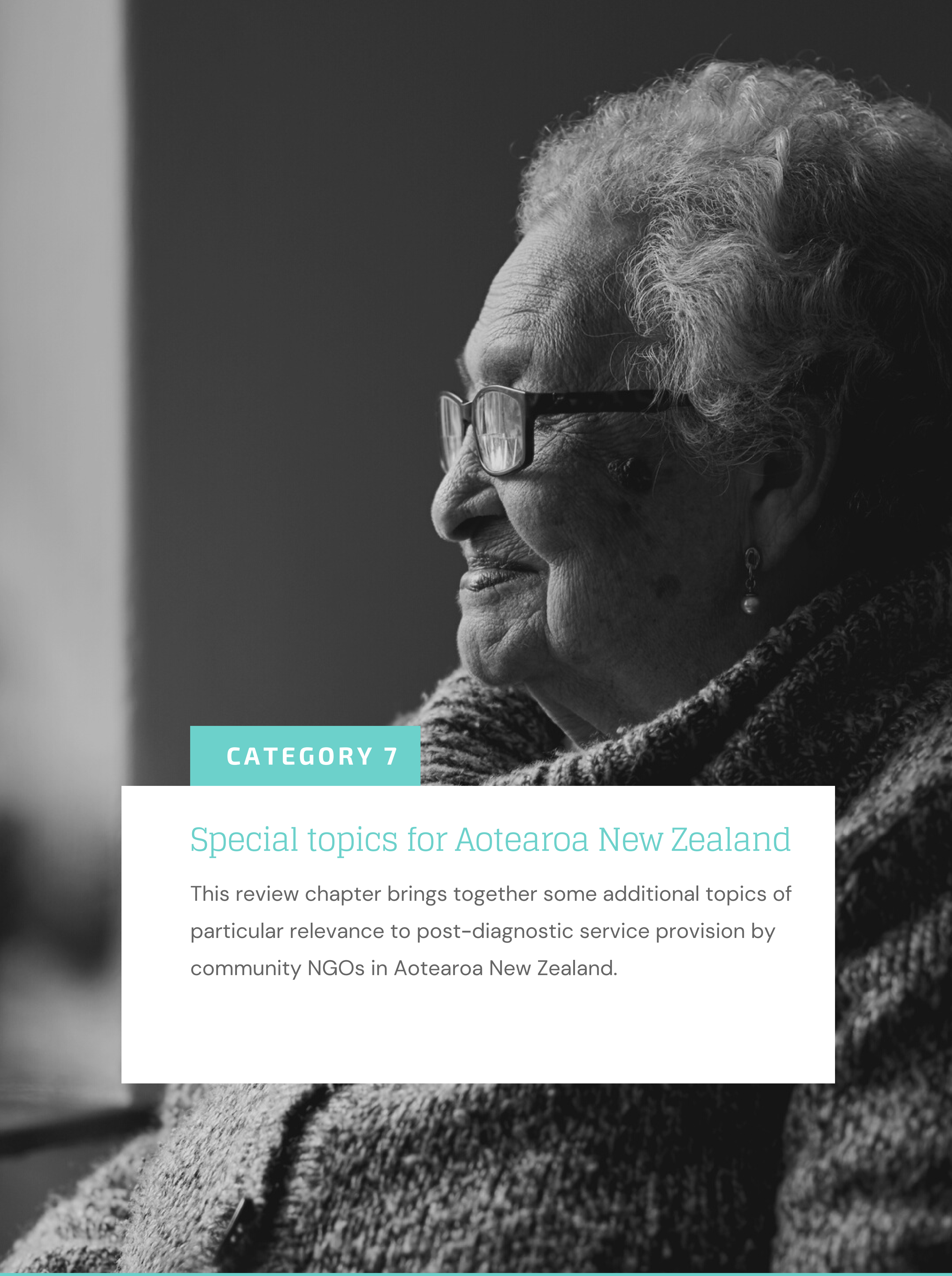

CATEGORY 7

Special topics for Aotearoa New Zealand

This review chapter brings together some additional topics of particular relevance to post-diagnostic service provision by community NGOs in Aotearoa New Zealand.

Special topics for Aotearoa

One of the main planks of the Pae Ora health reform process currently evolving in Aotearoa New Zealand is to make structural, service delivery, and commissioning changes in order to achieve more equitable health and well-being outcomes across the whole community, in particular in response to the on-going failures of the system to achieve the goals enshrined in Te Tiriti o Waitangi.

In addition, the government's adoption of the Dementia / Mate Wareware Action Plan as policy in 2022 has specifically required that the sector address equity in respect of Māori, Pasifika, rural, and young-onset dementia communities. This section of this project lays out literature relevant to community dementia NGOs considering their responses to these and related challenges as well as some features of the service development process that it may be helpful to consider.

Equity for Māori

Redressing the on-going effects of colonisation on the health of tangata whenua affected by mate wareware and thereby meeting the obligations for dementia services under Te Tiriti o Waitangi is a core aim of both the 2022 national reform of the health and disability system, Pae Ora, and of the Dementia / Mate Wareware Action Plan (Mate Wareware Advisory Rōpū 2021).

There are several signals from the academic literature that provide a basis for considering the co-design of community services for whānau living with mate wareware.

Dr Lorna Dyall (Ngāti Maniapoto) has written a detailed opinion piece on the links between colonisation and on-going health inequalities for Māori in relation to mate wareware and makes a strong case for co-design of whānau-based interventions to redress these issues (Dyall 2014).

The Māori Indigenous Health Institute of the University of Otago, Christchurch has published a summary of their "Meihana" model as it operates on that campus (Pitama 2014), including its links to other influential models such as "Te Whare Tapa Whā" by Emeritus Professor Sir Mason Durie (Rangitāne, Ngāti Kauwhata, Ngāti Raukawa). The authors' discussion serves as a very practical approach to improving the mihi / hui process between service providers and tangata whenua that can inform the process of co-design as well as influence the shape of kaupapa Māori mate wareware community services.

A consortium of researchers from Waikato and Tāmaki Makaurau have interviewed kaumātua from across the motu to distil matauranga Māori understandings in relation to mate wareware (Dudley 2019). The results are centred firmly in te ao wairua and explain why aroha, manaakitanga, and aspects of culture such as karakia, waiata, te reo, and tikanga are central to well-being for whānau affected by mate wareware.

Helpful insights from a qualitative exploration of the perspectives of pōua and tāua as well as clinicians (mostly Māori themselves) in respect of the concept of general "frailty" suggest that a kaupapa Māori approach to "cognitive frailty" might well be grounded in a balanced view of the accumulation of both strengths and vulnerabilities with ageing (Gee 2021). Perhaps the intrinsic value of older Māori might be seen as increasing even as functional abilities decrease, and some phenomena of mate wareware may be viewed as expressions of a gradual move into te ao wairua rather than as "symptoms".

A consortium from Tāmaki Makaurau published a framework for understanding a kaupapa Māori approach to assessing cognitive function derived from their work interviewing kaumātua, called "He Tūhonga Whaiaro" (Menzies 2022). This contribution forms a good guide that clinical services should use to understand where mate wareware co-design processes might lead.

An overseas group that sought to understand how ethnicity affects access and utilisation of dementia services by systematically reviewing the scientific literature made some potentially helpful observations, although none of the studies they review reference data from Aotearoa and few address groups that have survived colonisation (Cooper 2010). They noted evidence that ethnic groups that were minorities in their locales accessed diagnostic services later in their dementia journey and were less likely to access cognition enhancing medications, research trials, and aged residential care (noting that reduced uptake of aged residential care may reflect cultural strengths as well as vulnerabilities). There is local research support for the phenomenon of later presentation (in terms of severity at presentation, not age) from a study from Manukau (Cullum 2018). The primary solution derived from the literature review is for affirmative action approaches to improve access.

A consortium from Waikato and Tāmaki Makaurau worked with the Lancet Commission for Dementia to explore how ethnic differences in exposure to potentially preventable risk factors for developing mate wareware might predict different susceptibility of those groups to prevention measures (Ma'u 2021a). They predict a higher potentially reversible "attributable fraction" of risk for mate wareware for Māori than Pasifika, European, and Asian people in Aotearoa, mainly due to higher exposure to obesity and hearing loss for tangata whenua. Whether this translates into higher incidence and prevalence of mate wareware in Aotearoa New Zealand's current health and social context is not known.

Finally, co-designers should take notice of the format and content of the Mate Wareware information project for whānau developed by a group headed by Makarena Dudley (Te Rarawa, Te Aupōuri, Ngāti Kahu). This mahi culminated in a free internet application which has proved to be very acceptable to the community (www.matewareware.co.nz), combining accessible and appropriate information with culturally appropriate communication.

Special population groups

This review did not seek to be comprehensive in respect of the many other sub-populations in Aotearoa New Zealand that may have significantly different needs in respect of dementia services. In no particular order, these groups include:

- People with dementia in rural settings,
- People developing dementia in the context of intellectual disability,
- People with dementia in the context of co-morbid enduring psychiatric illness,
- People with dementia in the context of other neurological illness, such as Multiple Sclerosis or Parkinson's Disease,
- People with dementia in the deaf community,
- People with young onset dementia,
- People with dementia from any and every culture represented in Aotearoa New Zealand, especially Pasifika and Asian cultures, and
- LGBTQIA+ people with dementia.

Rural settings

There is some literature to guide service development for rural settings. The most recent review took a barriers / solutions approach, highlighting limited access to support and education services, especially for respite and day programmes; poor community knowledge of services that were available; and practical problems such as transport and financial barriers (Bayly 2020). The authors advise the use of person-centred approaches, use of technology to improve access, enhancing collaboration between services, and providing for single points of entry to those services that are available.

A pair of earlier reviews by the same authors found the same things: one looked at informal care and concluded that the key distinctive feature of rural versus urban environments is that rural family care partners have little to no access to support from formal services; that stigmatising views of dementia pose difficulties; that those services that do exist don't meet their needs well; and that they have few educational opportunities (Innes 2011). The other review examined formal care provision and advised overcoming the barriers by investing in rural-specific dementia services, providing case management in particular; developing the capacity of existing general health services to manage dementia; and increasing the use of telehealth technology (Morgan 2011).

Intellectual disability

Another group of special interest is people with a lifelong intellectual disability who develop a dual diagnosis of dementia. A recent thorough systematic review of psychosocial interventions for this population identified 21 studies that met the review's criteria. Although all studies reported benefits for the people involved, study heterogeneity prevented broad conclusions from being made (MacDonald 2020). Interventions included a range of behavioural strategies for use with the people living with dementia themselves, attempts to improve the models and systems of care used by care staff, input for the people living with the person with dementia (including flatmates with intellectual disability in supported accommodation), and specific therapies. These latter were often adaptations of the same interventions used with general dementia populations outlined in this report.

A transatlantic consensus statement of clinical and academic experts concluded that an ideal post-diagnostic community service would include similar ingredients as those for people with dementia who were not born with intellectual disabilities: access to counselling, psychoeducation, and support both for the person themselves and for their care networks; regular clinical review with a focus on quality of life, psychological health, and medical health; and proactive management of any such issues that arise, in particular from co-morbidities such as epilepsy (Dodd 2018).

In this country, an intellectual disability-specific pathway for the assessment and management of dementia has been prepared but is yet to be launched by the New Zealand Dementia Foundation on behalf of the sector. In respect of post-diagnostic support, it seeks to link existing service providers together better by providing more consistent assessment approaches and by enhancing awareness of local services, rather than promoting a particular post-diagnostic support model of care.

Young onset dementia

Young onset dementia has become more important to services since the baby boom cohort reached 55 years of age: the epoch from 2001 to 2020. This cohort effect will have a long tail. A 2020 document on young onset dementia prepared for the Irish National Dementia Office provides the most comprehensive review of the international literature as well as providing a thorough review of the post-diagnostic services situation in Ireland (Fox 2020). Important findings were that younger people with dementia found it difficult to access post-diagnostic services and those that did often found them inappropriate to their needs because of the age and sub-culture of other clients, the venues (such as residential care), and due to their special educational and support needs. In particular, employment needs, financial support requirements, and the needs of those supporting young children were highlighted as requiring different support. A broad range of recommendations are made, most particularly that a named case manager is essential.

An earlier systematic review focussing on psychosocial management for younger people could only identify three studies, all of which were centred on work-based strategies (Richardson 2016). Although such services are clearly important for the maintenance of identity and a sense of purpose, the paucity of research on care partner needs and experiences was noted. In a literature review of service models for younger people with dementia from an Aotearoa New Zealand (and to a lesser extent, Australian) perspective (Chaston 2011), the author concludes that the voice of people with young onset dementia is often missing from the literature. Where their views have been sought, people with younger onset dementia emphasise early diagnosis, psychoeducation, and service navigation provided by a case manager.

Of note, Dementia Cafés were mentioned as an acceptable model for service delivery. Related to this identified need to hear the voices of the people with lived experience, a recent report surveyed the opinions of people with young onset dementia in the UK in respect of the service options they valued (Stamou 2021). If one theme can be said to emerge from those data, it is 'enablement'. Successful services enabled access to other people affected by young-onset dementia, to specialist advice, and to physical and mental healthcare; and enabled social participation, speaking up, maintaining independence in the face of risk management, financial stability, and maintenance of family relationships.

Asian

Rather than reviewing international literature on dementia services for people from Asia including the Indian sub-continent, several excellent local resources were able to be surveyed. Indian New Zealanders' lived experiences of dementia were studied in a beautiful qualitative study from Auckland (Krishnamurthi 2022). Unsurprisingly, culture-specific service gaps were noted, yet standard services were nevertheless usually well-received by families and people with dementia. Specific cultural and religious understandings of dementia were highlighted, particularly the idea that dementia-related changes were a normal part of ageing or that they were related to karma. Participants expressed a fear of social stigma and loss of independence caused by dementia. Caregivers expressed a sense of the duty to care for family members, tempered by concerns about how this would affect their own health and well-being. Dissatisfaction with standard services mainly centred around wait times, delayed diagnosis, and the lack of culturally appropriate aged residential care options.

The importance of de-stigmatisation has also been highlighted in other New Zealand work exploring Chinese (Cheung 2019, 2022) and more general Asian (Punchihewa 2013) perspectives. A collaboration between the University of Auckland and Alzheimers Auckland (as it was then known) concluded that collaboration with Asian community partners is the key to improving dementia service utilisation (Punchihewa 2013).

LGBTQIA+

LGBTQIA+ citizens' needs have become increasingly recognised as an issue for service development, especially in respect of hospitalisation and aged residential care. In the context of dementia, the most important recent review focuses on research looking at the needs of the care partners in queer relationships (Di Lorito 2021). The particular experiences that were highlighted in the 20 studies surveyed by the authors included a loss of their identity in the queer world as they took up a care partner role, tensions around whether or not and how to 'come out' to health and social service providers, the positive or negative effects of key events in their own life and/or their community's history in respect of queer people, and the difficulties that occur when 'families of choice', created from social networks because families of origin were not supportive, are not recognised. Barriers to accessing good care included poor representation of LGBTQIA+ people in services, negative or uninformed attitudes from staff, and caregiver reluctance to reach out for help. The limited cultural competency of staff was identified as the biggest barrier overall. Strategies to overcome this included awareness programmes for services and staff, and signalling inclusive attitudes in services' online and written material as well as venues for care delivery.

Pasifika

Although the "Pasifika" label is being increasingly used in the sector to reflect growing awareness of health inequities, cultural needs, and community strengths, "Pasifika" culture is not a monolithic construct. Rather, in New Zealand there are important Samoan, Fijian, Tongan, Cook Island, Niuean and several other communities, each sharing some key characteristics with their Pacific neighbours whilst maintaining their unique qualities, not least their language. The peer-reviewed scientific literature on the experience of dementia by these communities is not well-developed, and most Pacific languages do not yet have agreed non-stigmatising words for dementia. These are important gaps. Interestingly, the scientific literature that does exist (Johnston 2018, Leung 2019, & Williams 2021) echoes the same themes that were uncovered by a more in-depth community talanoa on dementia service development hosted by the Tonga Ministry of Health in partnership with the Asian Development Bank in 2019 (Croucher 2019):

- Barriers to accessing dementia services include low community knowledge about dementia, strong community stigmatisation of dementia, limited family resources to enable access to health services, and very limited availability of services, especially outside of larger cities.
- The strong orientation of families towards caring for their elders, to the extent of extreme risk aversion in order to prevent any harm from befalling them, can combine with a strong sense of shame arising from the stigma of their elders being seen as "crazy", to generate a major cultural pressure to sequester people with dementia within family homes, away from their communities.
- Accessing traditional healers for input and asking respected (often Christian) religious leaders for assistance, especially for prayer, are key strategies adopted by families to manage the challenges posed by dementia instead of or alongside approaching health professionals.

For Pacific Island people in New Zealand, added barriers that clinicians are aware of from day-to-day clinical work include the lack of cultural appropriateness of services and the necessary reliance by health providers on a small pool of translators, who are often well-known people within their communities, who may be perceived as a risk to the family's safety from shaming.

Cost effectiveness

Funders typically ask for cost effectiveness data in respect of any new treatment or new service configuration and dementia services are no different. However, four main barriers work against the provision of such data for the types of services community NGOs might offer.

- First, there are few specific Aotearoa New Zealand data on which to base health economic analyses.
- Second, there is a corresponding lack of investment in dementia research in this country.
- Third, there is an international bias towards funding pharmacoeconomic analyses because few non-pharmacological interventions generate capital in and of themselves.
- Fourth, it is difficult to parse the signal from the noise in intervention studies of any kind because the effect of single interventions on important hard outcomes such as entry into aged residential care and death is highly multifactorial and significantly delayed.

Some researchers have argued that the main important 'goods' that arise from psychosocial interventions for dementia do not lend themselves to pricing for economic analysis in any case, in particular improved quality of life (Mittelman 2016).

Although no direct studies of cost effectiveness of dementia management strategies have been carried out in Aotearoa New Zealand, a detailed prospective economic evaluation of costs due to dementia has been published, indicating that direct costs rise with dementia severity (both behavioural and neuropsychiatric symptoms and functional disability), that the informal care partner costs are staggering, and that low income status for families affected by dementia increases carer stress in part because of the informal and opportunity costs they absorb (Gallrach 2010).

Repeated economic impact reports commissioned by Alzheimers New Zealand from Access Economics (part of the Deloitte group) and most recently an updated report from the University of Auckland (Ma'u 2021b) estimate that around a third of the economic impact relates to the unpaid work carried out by citizen care partners, another third is direct payment for aged residential care relating to dementia, and the final third is mainly made up of medical rather than social services costs. The total cost to the government in 2020 was estimated to be $2.46 billion with a projected rise to $5.9 billion by 2050 (in 2020 New Zealand dollars). The authors of the latest study note that their 2020 estimate based on up-to-date population and service utilisation data was considerably greater than had been predicted by the previous Economic Impact Report in 2016.

The provision of aged residential care is the single largest cost borne by most comparable health and social service systems internationally, given that most people with dementia and their families would choose to remain at home for as long as possible. In addition, delaying entry into care is potentially achievable using feasible interventions. This means that measuring time to entry into aged residential care (or similar metrics) has repeatedly been chosen as the outcome of interest in cost effectiveness analyses in the dementia setting, despite the problems outlined above. Delays of even six months are highly significant in terms of cost savings, especially given the evidence that current dementia treatments do not typically extend the lifespan.

The most recent systematic review and meta-analysis of studies directly seeking to influence entry into care with non-pharmacological interventions could only demonstrate limited support for an effect, finding a 33% reduction in aged residential care admission rates over 12 months from community care coordination (essentially case management including service navigation) and no effect from other modalities of intervention (Lee 2019). Updating an earlier review looking at care partner interventions overall (which had shown a benefit from care partner interventions on institutionalisation (Pinquart 2006)), a recent meta-analysis of meta-analyses failed to demonstrate a benefit from care partner-specific interventions (Walter 2020). Another review concurred that case management was the only intervention linked to delayed institutionalisation in an analysis of studies aiming to improve quality of life for people with dementia and their care partners (Zabalegui 2014).

Still earlier, a high grade of evidence was pooled to demonstrate the effect of multi-modal care partner interventions on entry into care in a systematic review of nonpharmacological therapies in Alzheimer's disease (Olazarán 2010), again, demand was reduced by about a third. The essential components of these interventions were said to be counselling, support, psychoeducation, and individualised assessment. One of the studies (using the Mittelman NYUCI intervention) was associated with an estimated delay of more than a year. A still earlier study included a meta-analysis of ten studies of multi-component interventions and reported the same thing: multiple trials showing evidence of community support programmes delaying rates of institutionalisation, with a pooled benefit of around 33% reduction (Spijker 2008).

In addition to these data, other sections of this review have also presented economic evidence to support the impact of various interventions on institutional care costs where appropriate. Service providers would be forgiven for concluding that the reason funding bodies have held back from commissioning comprehensive post-diagnostic services for people with dementia in Aotearoa New Zealand is not a lack of evidence of cost-effectiveness but a lack of will, particularly since comparable nations have been doing so as a core component of their dementia management strategies for ten years or more.

This problem is not unique to Aotearoa New Zealand. A key structural barrier that has been identified is that the budget for aged residential care and the budget for provision of community services are usually separate, mitigating against creating an incentive to take action. However, the argument needs to move on to how to implement service development - further health economic demonstrations would not seem to be required.

The process of service development

Four recent and thoughtful British papers are of special interest to service providers and commissioners in this country in respect of implementing the decisions they will make about improved post-diagnostic services.

A review of the process of actualising the National Dementia Strategy in England highlighted the main barriers to successful implementation: services or parts of the sector having insufficient capacity, knowledge and skills to deliver what is being expected of them; insufficient proactive review being built in to the system; a lack of holistic underpinning philosophies or models of care; and fragmentation between different parts and providers within the sector (Wheatley 2021). The authors recommend a range of strategies to overcome these based on the experiences of successful services.

A British group reviewed the scientific and grey literature in pursuit of key learning points that could be used by community dementia organisations seeking to improve the sustainability of their post-diagnostic services, generating a wealth of practical advice organised around several themes: ways of finding and keeping members, staff, and volunteers; maximising the support of other providers in the dementia space; and obtaining and managing funding (Morton 2020). The authors recommend a range of methods to achieve these goals based on successful services.

Echoing previous work, a qualitative study that interviewed people with dementia and their family care partners was able to identify some of the key factors that influence how readily affected people avail themselves of community post-diagnostic services. The study identified the main factors to be: individual responses and adjustment to the diagnosis; the appeal and perceived benefit of the programmes offered; the context of the provider in the community; and the quality of relationships with workers and communications from the services (Field 2021). The authors detail these responses in a way that can inform appropriate marketing to facilitate good access to services.

Finally, a modified Delphi approach including people with dementia as well as family and clinical voices was used to identify the most important outcomes that should be considered for measurement for post-diagnostic services (Reilly 2020). The outcomes themselves are strong findings but perhaps for the Aotearoa New Zealand environment a more appropriate arrangement of their domains would be: dementia-friendliness of home and neighbourhood; engaging in meaningful activities; managing several key dementia-related symptoms better; avoiding falls; and maintaining personhood.

Summary: Special topics

The Pae Ora health reforms provide the most important opportunity of a generation to co-design accessible, appropriate, and effective dementia services with all communities in Aotearoa New Zealand. To be effective at addressing equity concerns, these services are unlikely to be 'business-as-usual' modified to look more appropriate from the cultural perspective of whatever group is being considered, be that tangata whenua, rural New Zealanders, Pacific Island families who are living in New Zealand, or citizens who develop dementia at a young age. After all, 'business as usual' is what has already been shown to be ineffective at addressing inequity in other areas of the health sector. Instead, it will require dementia service providers to meet directly with the communities involved to understand what they need, and to add the dementia sector's knowledge and experience to the strengths of those communities in order that something new can be developed. There are helpful signals in the literature that can prepare the partners for this endeavour, but they do not amount to service blueprints.

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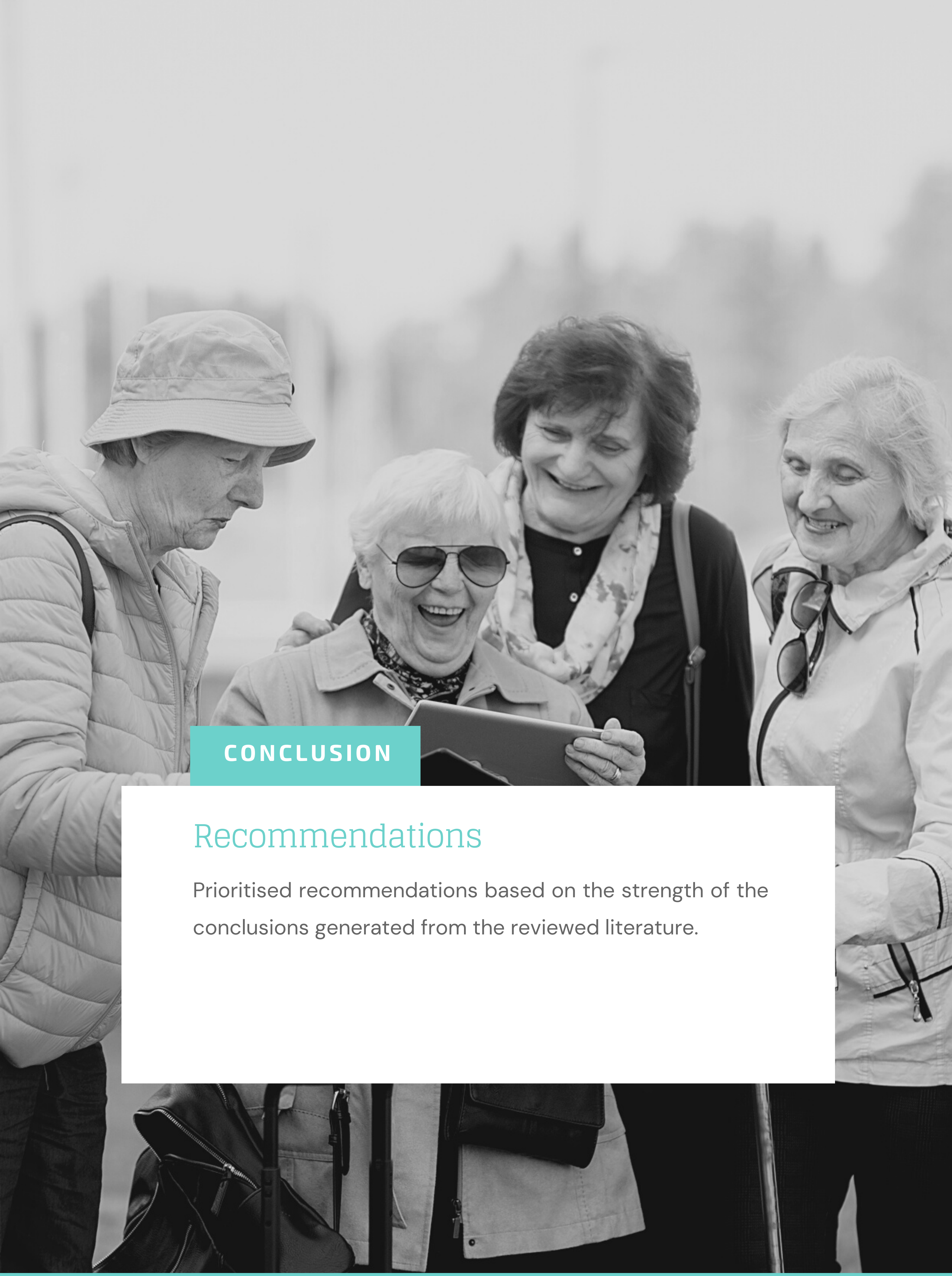

CONCLUSION

Recommendations

Prioritised recommendations based on the strength of the conclusions generated from the reviewed literature.

Recommendations

This report provides an updated review of recent literature as well as analysis of best practice approaches for core post-diagnostic community dementia services, in an attempt to reach optimistic and specific conclusions about what should be commissioned from and provided by Dementia New Zealand affiliates and related groups in Aotearoa New Zealand.

Post-diagnostic community services for people with dementia are currently mainly provided by the local affiliate organisations of Dementia New Zealand and the member organisations of Alzheimers New Zealand. There is as yet no nationally agreed underlying philosophy of care, no agreed service delivery model, no agreed commissioning and funding arrangement, and no agreed ranking of services that could be provided from essential to peripheral.

Work is under way by the two dementia-specific NGO groupings to address these gaps but national commissioning decisions will clearly need to be taken. Even the best funded health districts in the country in terms of the dementia sector are inadequately resourced in the face of the current need for post-diagnostic care in our communities, let alone future needs. Besides failing individuals, families, and whānau, this poses a major risk to the health sector due to missed evidence-based opportunities to "flatten the curve" of downstream demand, especially costly hospitalisations and entry into aged residential care. Furthermore, even the more developed health districts cannot mobilise services to prevent the unmet need arising from barriers against provision of accurate and timely diagnosis across all healthcare settings, which occurs in part because of the persisting myth that 'there's nothing you can do and diagnosis just upsets people'. All of this is compounded by the added risk to the health and social services sectors posed by the rapid increases in the absolute numbers of New Zealanders with dementia due to the ageing population. The sector is therefore not able to meet the community's needs, and this is no surprise: it is neither designed nor resourced to do so.

What, then, can be said to be 'best practice' in respect of post-diagnostic community services in Aotearoa New Zealand for people with dementia and their care partners, from the perspectives of experts and service providers, as well as from the scientific literature, in light of our social and political realities? In short, the answer to this question provided by this literature review is:

The national Dementia / Mate Wareware Action Plan has largely enunciated the correct first steps in respect of the process required to reorganise and improve post-diagnostic services in this country.

The following recommendations are organised according to the strength of the conclusions in the evidence base.

CORE RECOMMENDATIONS

Considered to be an essential element of post-diagnostic services on the basis of the literature reviewed: a priority for resourcing.

1 Multi-modal programmes should be considered the norm for post-diagnostic dementia community services, and every programme should explicitly outline its multiple aims and methods so that facilitating staff and participants understand the potential benefits and so that no important goals are missed.

2 Post-diagnostic community dementia services should reach national agreement on their underlying service provision goals and general methods and be able to describe how these flow from their underlying philosophies of care.

3 Post-diagnostic dementia service outcome measures should be nationally agreed in line with this literature review's findings about what matters most to people with dementia and their care partners, in light of the Dementia Declaration put forward by Alzheimer's New Zealand's Advisory Group.

4 All people should have a named case manager for the duration of their journey through post-diagnostic dementia community services.

5. The provision of personal and emotional support should be integral to all post-diagnostic dementia community service interventions, provided to both the person with dementia and their care partners, with explicit links to the underlying philosophy of care of services and clear service provision implications.

6. Psychoeducation should form an integral part of post-diagnostic dementia community services, and be offered to both the person with dementia and their care partners. This must be tailored to the sociocultural milieu of the attendees, most particularly the cultural affiliation of participants, especially for tangata whenua.

7. Formal cognitive stimulation therapy (CST) should be available as a component of all post-diagnostic dementia community services, following the standard protocols of that programme.

8. All people with dementia who identify as Māori as well as their whānau should have access to a specific post-diagnostic service co-designed with local iwi or a delegated authority, via stand-alone kaupapa Māori services or, if necessary, a co-designed adaptation or sub-component of a generic local service.

9. Nationally, work should be done to systematically co-design service adaptations or stand-alone post-diagnostic dementia service options for the special people groups identified in this review (especially Pasifika, rural, and young-onset dementia communities, but also people living with dementia alongside enduring mental illness, major central nervous system neurological illnesses, and intellectual disability; as well as people with dementia in the deaf community, and in other ethnic / cultural communities including LGBTQIA+ people.

INTERMEDIATE RECOMMENDATIONS

Considered to be of intermediate importance for inclusion in post-diagnostic services on the basis of the literature reviewed: second tier priorities.

10 Navigation assistance for broader dementia services should form a formal part of the offering of post-diagnostic dementia community services.

11 An individualised care plan should be negotiated with all clients that maps to the underlying philosophy of care and service provision goals of the suite of services made available.

12 Psychoeducation is best presented as part of a multi-modal programme offered in a group setting that both the person with dementia and their care partners attend, albeit in separate streams as appropriate to the content.

13 Personal and emotional support programmes should generally be provided to the person with dementia as well as their care partners, albeit possibly via separate streams.

PERIPHERAL RECOMMENDATIONS

Not considered to be essential for the provision of post-diagnostic dementia community services from an evidence-based perspective, but still relevant: for consideration if resources allow.

14 Personal and emotional dementia support should include formal options structured using a Dementia Café or Meeting Centre format.

15 Personal and emotional dementia support services should include the provision of a helpline made available to all current and past service-users - that is, for the whole of the dementia journey.

16 An exercise programme, not necessarily following a formal programme, should be included as part of post-diagnostic dementia community service programmes.

17 Life story work should be available in all post-diagnostic dementia community services.

18 The arts should be included as part of what is available in post-diagnostic dementia community services.

19 Dementia community service provision frameworks should specify how services will actively work towards equity of access and equality of outcomes in respect of the special populations mentioned in this review (see recommendation 8 and 9 above, as well as the categories listed in the Introduction Section from the UK's Equality Act 2010).

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Disclaimer: These recommendations reflect the personal views of the authors in light of the review process and do not necessarily reflect the views and positions held by the New Zealand Dementia Foundation and its trustees, employees, and members.