

Developing More Flexible Approaches to Respite for People Living With Dementia and Their Carers

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A vital aspect of the care of people living with dementia is the provision of respite services, which allow family caregivers a break from the caring role. The flexibility of such services has consistently been identified as a major factor in whether families make use of them. This study of dementia respite services explores the notion of flexibility and then presents a comprehensive checklist that

respite service providers can use to assess the flexibility of their service. It then provides brief descriptions of a number of creative respite programs that are examples of flexible service provision.

Keywords: respite; dementia; flexible service provision

Dementia is already a major medical and social issue that will increase in importance into the future. In 2000, there were estimated to be 4.5 million persons with Alzheimer's disease in the United States, and it is predicted that this figure will rise to 13.2 million by 2050.¹

Supporting the role of family carers has been widely accepted as a fundamental plank of dementia care policy and practice.²⁻⁵ One of the most important strategies for supporting carers is through the provision of respite services.⁶⁻⁸ Respite involves some kind of break for a carer from the pressures of their caring role.⁹ Such a break can be the outcome of many different types of support that a carer may receive, such as help with personal care, a regular visit from a friend, or attendance at a carer support group. The term *respite services* commonly refers to services or programs that provide short- or medium-term substitute care of the person being cared for.

While there have been very few controlled studies of respite,¹⁰ there have been many noncontrolled and evaluation studies that have indicated its

importance.¹¹⁻¹⁵ A number of reviews and commentaries have reported on the need for respite services to be more flexible.^{5-7,16}

This article will explore the concept of flexibility and how service providers can assess this within their own organizations. It will also provide examples of flexible respite service provision. The information is based on a research project funded by the New South Wales, Australia, state government to expand the flexibility and accessibility of dementia respite services in that state.¹⁷ Data collection for this project included interviews with staff members from 22 dementia-specific respite programs, staff and volunteers from 26 day programs for frail older people, staff from 10 services providing multicultural dementia care, and a focus group of carers of people living with dementia.

Understanding the Notion of Flexibility

Flexibility in respite provision can be seen on 2 levels: how the service operates internally within the constraints of its own funding and how well the service is networked with other respite providers in an effort to facilitate the best system possible for the local area.

How the Service Operates Internally

The first indicator of flexibility is how thoroughly staff members assess and respond to the needs of the carer and the person living with dementia. A flexible

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service will look at all the needs and see in what ways the service can cater to these needs. This is in contrast to an assessment approach that is mainly concerned with whether the client fits the program criteria.

The service provider needs to really understand the concerns and issues of the person with dementia and his or her carer. This is particularly the case because carers may be reluctant to use respite services if they feel the person with dementia will not get good-quality care or that the problems will outweigh the benefits to him or her.^{18,19}

Other areas in which individual services can demonstrate flexibility are staffing policies and practices such as staff selection, development, training and support; management practices such as service review and evaluation, planning procedures, and feedback from carers; type and range of program(s) offered; operating times; and policies that address the cultural diversity of the local community.

How the Service Networks

The second main way that flexibility is manifested is how well the service is networked with other services. This is because one service—no matter how flexible—cannot possibly provide all the many and varied forms of respite that carers need. In the first instance, a flexible service will know about other services in their local area. They will also assess the carer and the person living with dementia, knowing that these other services are available and may be drawn on in developing a care plan.

A further indicator of flexibility in terms of networking is the degree to which the service provider takes responsibility for promoting local solutions to gaps in respite provision. Service providers who are truly concerned about the needs of carers will not be satisfied if they have a good service but find carers' needs are being significantly unmet in other ways. They will work actively with other service providers and consumer groups to share resources, set up cooperative ways of working together, lobby for new services, and apply for new funding to help fill these gaps.

Flexibility Checklist for Respite Service Providers

This checklist (see the appendix) is a practical tool for respite services to use in assessing how flexible they are in the way in which they provide

respite. The checklist makes a number of statements that reflect a flexible approach to working, and the respondent marks whether this statement is “met,” “partly met,” or “not met.” The checklist is divided into a number of sections in terms of the approach to flexibility introduced earlier in this article.

Services can use the checklist in several ways. They can use it as an overall assessment of the service by just ticking the boxes and getting an overall picture of how flexible the service seems. Alternatively, they can invest more time and write in why they answered each statement the way they did. This will allow a more thorough analysis of how the service is working. A third use of the checklist could be to focus on parts of the checklist only if specific issues had already been identified as problems.

Examples of Flexible Approaches to Respite

This section provides a number of examples of flexible respite provision. While there will be many other examples of flexible programs beyond this list, these examples are put forward to stimulate ideas and share the experience of many creative workers in the field. While some examples are drawn from the literature, most are based on the author's field-work experience in undertaking the research project introduced above.

Host Family Day Respite

Geared particularly toward people in early-stage dementia, this type of program involves a paid worker offering his or her home as a meeting place for a group of up to 4 people living with dementia. It is set up more as a normal social gathering than as going to a formal respite center. Host family care workers are carefully selected, given orientation, and supported by a program coordinator.²⁰

Host Family Overnight Respite

Host families are carefully selected, trained, and supported. They then make their homes available for overnight stays by people living with dementia who need respite. The care is set up as if the client is just “staying with friends” for a couple of nights. Receiving respite in this way is more natural and less threatening than going into a nursing home or hostel.²¹

Overnight Stays at Day Centers

The roles and functions of day centers have changed in recent years to reflect the needs of frail older people, people living with dementia, and their carers. The environment has become more home-like, and hours may be extended into the evenings and weekends. As the day centers have evolved to meet the needs of carers, one further development has been their use for overnight stays. Some of the advantages of overnight respite as outlined by Byrne²² are that it provides greater options for carers and provides continuity of care in a familiar, safe, and homelike setting.

Social Outings as a Form of Respite

Respite services do not have to always be offered in a formal setting such as a day center. People with dementia may be taken as a group to a picnic, a walk along the beach, or a meal at an open-plan dining room at a local club or restaurant. This helps to provide some sense of normality in their lives. The carer may go along as part of the group or may use this time to pursue his or her own activities.

Holiday Programs

A number of respite services offer holiday programs. They may cater to carers only, people living with dementia only, or both. There may be a fee for carers and/or contributions from the service provider. Sometimes services may get sponsorship for the holidays from local clubs or community donations.

Respite Provided With Intensive Carer Education and Support

This approach to respite focuses on the needs of both the person with dementia and the carer. The person with dementia will receive services as determined by his or her needs, while the carer will be offered education and support. This may include the worker's developing and modeling practical techniques to manage problematic behavior. This type of program may be offered in the community or in a residential setting.²³

Day Center With Extended Hours

Too often, community services such as respite day centers operate on a 9-to-5 basis, often so that

staffing is more manageable and affordable. But this will not suit many carers, especially those who are in the workforce. One indication of flexibility is when services can have extended hours and can help out by providing breakfast or an early evening meal, which will take some pressure off the family carer.

Day Center Run in Conjunction With In-Home Respite

There are great advantages in having a day center and an in-home program run under one umbrella. It means that both services can work together in catering to the needs of individual clients. This may occur if the person needs a mix of in-home and day center care. It is also helpful if the person's circumstances and needs change and they can still be looked after by the one service rather than being put off one service and having to apply to another one.

Programs for Specific Target Groups

Many people living with dementia or their carers may not want to take part in respite services if their particular cultural background or specific issues are not addressed by the program. Respite service providers should be aware of the needs within their local community and organize programs to reflect these needs as much as possible. Examples of programs aimed at specific target groups include those for people from specific language or cultural backgrounds, younger people with dementia, and people with HIV/AIDS dementia.

In-Home Occasional or Emergency Respite

This approach is unusual in that it does not provide a permanent or ongoing respite service. It is based on the finding that carers often need occasional respite for special occasions or because of an unforeseen event. The specific service provided is usually negotiated with the carer according to his or her need. If a carer makes regular calls on the service, this can be taken as a sign he or she may need to be referred to another organization that provides more ongoing support.

Residential Respite in a Noninstitutional Setting

Carers often require respite for 1 or more weeks, which usually means that the person with dementia

will be cared for in a nursing home or hospital setting. It will be much better if he or she can receive this care in an environment that is as familiar and homelike as possible. Some organizations provide a cottage-style respite service where the person has his or her own room and the daily routine is more low key and familiar than in a larger, more institutional setting. This approach works well if the cottage is part of a complex of other services such as a hostel, nursing home, or hospital.

Day Respite Offered by a Nursing Home

Some areas have no day centers for people with dementia, while they may have a good supply of nursing homes. Under this approach, the nursing home uses some of its physical and staff resources to provide day respite service to people living in the local community.

Mobile Respite Service

This approach is particularly relevant for rural and remote settings. Commonly, 2 people work together and visit different locations in the country for set periods of time. They may offer one-to-one respite, carer support, and education or group programs, depending on the needs of individual families. A variation of this is where a day center program is offered in different locations on different days of the week.

Respite Combined With Providing Something Special for the Carers

While the person with dementia is being cared for, a special effort is also made to promote the well-being of the carer. This may be through a regular meal together or a day on which carers are treated to entertainment, manicures, massages, and other forms of pampering. These services may be provided by local businesses or community organizations as recognition

of the important role that family carers play in the community.

Respite Through a Leisure Buddy System

Under this approach, the person with dementia is paired with an age- and culturally appropriate peer to provide involvement in familiar and valued recreational and social activities within the local community. Past activities and interests are identified, and these are used to help find a suitable buddy. Buddies are recruited from existing community resources such as service clubs and volunteer community groups and provided with ongoing support by a program coordinator.

Conclusion

The number of people living with dementia in the community will continue to grow dramatically in the coming decades. The support provided to them by family carers will be a central part of the care of people living with dementia. Governments and health and community services need to find ways to creatively support people living with dementia and their carers.

Respite services are highly valued by carers, and research has shown considerable benefits from their provision. One aspect of respite care that has been regularly identified as important is the need for it to be flexible in its ability to accommodate the variable and often complex needs of carers. A framework has been provided for service providers to assess the level of flexibility in their own services.

There are many service providers who are providing creative and flexible respite services to people living with dementia and their carers. It is important that they conscientiously evaluate their programs and make efforts to disseminate their work to other service providers. Dementia researchers can address the current shortage of controlled studies of respite effectiveness by developing collaborations with respite service providers and helping to provide high-quality evaluation and intervention studies.

Appendix

Flexibility Checklist for Respite Service Providers

Column 1 = Met Column 2 = Partly Met Column 3 = Not Met	1	2	3
Approach to carers			
Initial assessments look comprehensively at the needs of the carer.			
Initial assessments look comprehensively at the needs and history of the person living with dementia.			
Initial and ongoing assessments recognize and acknowledge concerns and negative perceptions of respite that carers may have.			
Initial assessments consider the range of possible services that may be of help to the carer rather than just assessing for eligibility for the assessor's program.			
Information about respite alternatives is provided in a way that is appropriate for each carer. This takes account of the person's level of anxiety, literacy, and their cultural background.			
The service coordinator is prepared to make several return visits to the carer to help him or her make a decision about whether and how she or he wants to use respite.			
When a person begins respite, allowances are made to help him or her settle in. This may involve including the carer, allocating a staff member for one-to-one care, or having shorter periods of respite.			
Carers are encouraged and supported to seek help from family members and friends in caring for the person living with dementia.			
Some form of carer support group is offered by the service, or else carers are informed about local groups.			
Carers are kept fully informed of changes in the condition of the person attending the respite service.			
There are clear and open ways for carers to express concerns about the service, and an open mechanism is available for dealing with these concerns constructively.			
The views of carers are sought in service review and ongoing planning.			
Staffing policies and practices			
Selection criteria for positions provide for flexibility in who is employed rather than having highly specific requirements.			
There is a strong emphasis in staff recruitment on attitudinal skills such as empathy, active listening, and patience.			
Staff members' skills and experience match the type of clients they will be required to look after, especially if they are working with minimal supervision.			
Staff members' cultural and language backgrounds are acknowledged and used in developing care plans for clients.			
Terms of employment (eg, times and changeability of work patterns) allow for flexible service delivery.			
The number of clients and staff members is calculated to promote optimum and safe care.			
All staff members are provided with comprehensive practical training about working with people living with dementia and their carers.			
All staff members are provided with ongoing supervision and support in their work.			

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Appendix (continued)

Column 1 = Met Column 2 = Partly Met Column 3 = Not Met	1	2	3
Management practices The service has a clear profile of the local community as a basis for planning its programs.			
Policies, procedures, and guidelines are critically evaluated to determine whether they promote or discourage flexibility in the way the service operates.			
There is a clear process for review and ongoing planning of the service at least on an annual basis.			
If a significant problem occurs, there are clear reporting requirements and processes set up to critically reflect on the incident and develop positive responses to the problem.			
Local medical officers are kept informed if their patients are admitted to the program and if there are concerns about these individuals' condition.			
There is comprehensive data on clients as well as critical incident processes and annual carer satisfaction surveys as baseline forms of evaluation.			
There is input from staff and other service providers from the local network in evaluation and ongoing planning for the service.			
Type and range of program(s) offered The program does not duplicate other services in the local area.			
The program(s) offered are based on an assessment of local needs through participation in local network planning.			
Programs are adapted over time to cater most effectively to client needs.			
The service either offers several forms of respite or is closely linked to other services that do.			
There is a willingness to respond to complex needs that do not fit into the normal service and to find appropriate responses.			
Operating times The service is available at times that are needed by a range of carers, including those in the workforce.			
If the service is not available at times needed by a carer, efforts are made to accommodate the needs of the carer as much as possible (eg, arrange in-home care for a brief period, extend normal hours on those days, refer to another service).			
Catering to the cultural diversity of the local population The service has clear information about the main cultural and language groups in their local area.			
Contact is made with health and community workers from the main cultural groups to find out about the range of multicultural services available.			
Local multicultural health and welfare workers are fully briefed about the respite service.			
Information about the service is translated into the main local community languages and distributed through local community networks.			
A planned approach is adopted that includes people from different cultural backgrounds in the mainstream program.			

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Appendix (continued)

Column 1 = Met Column 2 = Partly Met Column 3 = Not Met	1	2	3
Clusters of people from the same language background are set up when there are numbers to do this.			
Partnerships are formed with ethnic community organizations to get their support and input into how the respite service is planned and run. They may be able to give direct assistance in areas such as providing volunteers, helping set up carer support groups, and liaising with ethnospesific nursing homes and hostels.			
Services lobby to have a pool of ethnic health workers who are based with a specific service but available to other agencies on request.			
Networking The service maintains a current listing of other services in the local area.			
The service works actively with other service providers to find creative respite solutions for clients that one service is not able to provide on their own.			
Staff members conduct joint client assessments with other agencies if there is a need for a range of skills and experience.			
There are clear policies and protocols about referral of clients to other local services.			
Staff members meet with other agencies to conference individual clients who use a number of services and have complex needs.			
Staff members attend meetings with other local services to share information and participate in areawide planning.			
Staff members provide education and support to mainstream respite services for older people (eg, day centers, social groups, in-home respite programs) in helping them provide appropriate care for people living with dementia.			
Service development, community education, and community development The service coordinator works actively with other service providers to improve the ways that respite is provided in the local area.			
The service coordinator works with other service providers to lobby for new and improved services in the local area.			
Staff members provide information and education about dementia and respite to community organizations with older people as members.			
Meetings are arranged, through local health and community workers, with ethnic communities to explain about respite and answer any questions they might have.			
Staff members initiate or support community development projects that aim to make community organizations more open and inclusive of members with dementia.			

What are the main areas in which flexibility has been “not met” or “partly met”?

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Appendix (continued)

What are some strategies your service can implement to gain a greater degree of flexibility in how it operates?

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How will these strategies be implemented?

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