

CONSULTATION ON DRAFT GUIDANCE FOR RESPITE CARE

The Scottish Government has recently started a consultation on Guidance on Respite. This guidance was developed as part of the Respite Task Group that was established as part of the recommendations from Care 21: the future of unpaid care in Scotland. The Task Group is made up of representatives from carer organisations (including Carers Scotland), voluntary organisations with a specific interest in respite and short breaks, health and local authorities and departments within the Scottish Government.

This document summarises the Guidance including an annex, which gives details of indicators of good respite and examples of good practice. A copy of the full guidance is available online at www.carerscotland.org.

Who is the guidance for?

The guidance has been developed to provide local authorities and health services with advice on planning and delivering respite and short care. These agencies are to use this guidance to update their planning of respite services and into their targets for improving local community care services. It also intended to be helpful to other interested parties including carers.

Why?

Respite care is an essential part of the overall support provided to unpaid carers and those with care needs helping to sustain the caring relationship, promote health and well being and prevent crises. The main purpose of the guidance is help local service planners improve respite provision in line with the overall principles of enabling self-care and working with carers as partners in care, by:

- improving the planning of respite and short breaks:
- shifting the balance towards preventative support; and
- personalising support to improve outcomes both for carers and those with care needs.

Expected Outcomes

The Scottish Government expects local authorities and health services to develop a strategic approach to local planning, delivery and evaluation of respite and short breaks and, through this, the delivery of a range of outcomes for carers and service users. The Government expects to see three main outcomes for carers and service users:

1. that carers and service users are involved in planning the shape, direction and level of local respite and short break services
2. that there is greater choice, flexibility and equity of provision of services
3. that carers and service users feel supported by the respite and short breaks provided.

Definition

Respite encompasses a wide range of different short term services. The common factor is not what service is provided but its purpose - *to provide a break which is a positive experience for the person with care needs and the carer where there is one*. Respite can be offered in a wide variety of ways including:

- breaks in respite-only units (specialist guest houses, community flats, purpose-built or adapted houses);
- breaks in care homes;
- breaks in the home of another individual or family who have been specially recruited (such as adult placement schemes);
- breaks at home through a care attendant or sitting service;
- facilitated access to clubs, interest or activity groups;
- holiday breaks;
- supported breaks for the person with care needs and their carer together;
- befriending schemes where volunteers provide short breaks;
- peer support groups (e.g. for young carers);
- breaks in supported accommodation; and
- breaks using self-directed support

Some forms of day care may also be seen as within the definition of respite. Although befriending is a service for the person needing care, it is included because breaks providing alternative recreation with a befriending escort, which are regular and long enough, can also provide a break for the carer.

Other support, such as providing minor equipment can be vital to help facilitate breaks in some of the above settings or in the home of family or friends.

Evidence of value of respite and purpose of respite

The main evidence of the value of respite care is based on the perceptions of carers, discussed in studies and the Care 21 report. The Guidance highlights that respite is effective in:

- helping carers to safeguard their health avoiding physical or emotional exhaustion, and enabling them to continue caring;
- preventing social isolation - providing a break from their usual routine for people with care needs and carers, enabling them to take part in leisure or other activities;
- overcoming a crisis, such as the carer not coping, cared for person's health deteriorating, or bereavement;
- making time for carers to spend with family and friends; and
- helping people (particularly those cared for by their parents) develop independence and prepare for the time when the carer cannot continue caring.

Respite was found to be most effective in providing a break for carers when they were confident in the arrangements and did not need to worry about the person with care needs. This finding supports the observation that some carers and those they care for can be unwilling to take up some types of respite and reinforces evidence for the value of choice and personalisation in respite provision. In particular, respite is seen as effective in preventing crises and supporting those with care needs and their carers to maintain their health and continue living

at home. For young people respite provides opportunities to participate in activities with their friends and peers vital to their personal, social and educational development, contributing to their self-confidence and wellbeing.

Strategic Planning

The Guidance notes that there are still considerable differences in how and to what extent authorities have planned their respite services. It notes that authorities need to apply the same rigour to respite services as they do for services in the round. This will require agreement on how plans will be developed and coordinated, what resources are available and how these will be directed.

These strategic plans for respite should set out a systematic joint approach for the delivery of both planned and emergency respite, including care/carer assessment, eligibility criteria, staff training and information.

They should also include measures for monitoring provision and need, involving those who use the services in reviewing them against agreed standards. They should address transitions from children to adult services and from adult to older peoples services. Plans should identify responsibilities for delivering measurable short, medium and long-term goals and be based on:

- a shared vision setting out the shape and direction of service development;
- clearly stated targets for improving services;
- multi-agency development and delivery, involving Local Authorities, NHS, carers and service users, voluntary sector organisations and service providers; and
- clear understanding of the range and volume of provision, its strengths, weaknesses and gaps, based on local needs including feedback from service users and carers.

The Guidance also notes that local authorities have a duty to children and young people and in planning respite and short breaks for young carers and carers of disabled children.

- under the Children (Scotland) Act 1995, to safeguard and promote the interests of children in need, including disabled children and young carers and, to assess the support needs of children and, where appropriate, their carers, which can include respite.
- under Arrangements to Look After Children (Scotland) Regulations 1996 which regulate short term placements for children. The National Care Standards will also apply to the provision of such placements. However, the NHS should work closely with its partners to ensure that the need for short-term (respite) placements is identified for looked after children and others with specific medical, physical and behavioural needs and their carers, including parents, kinship and foster carers.

Joint Planning and Resourcing

Authorities are advised that they need to consider their joint planning, where resources need to be shifted and the implications of this and, where the primary responsibility for specific types of respite lies. For example, in the past short-term care (respite) previously provided by the NHS for people whose needs are mostly for social care is often now commissioned by local authorities. Community Care Partnerships need to plan changes together, with the involvement of users and carers. NHS Boards and local authorities should agree their complementary responsibilities for short-term health care respite and social respite care, both planned and emergency. Local

authorities are responsible for respite for people assessed as needing it for social care and NHS Boards are responsible for addressing the needs of:

- people assessed as having complex or intense health care needs and who require specialist clinical supervision during a period of short-term care;
- people who require or could benefit from active rehabilitation during a period of short-term health care (respite);
- people who are receiving a package of palliative care in their own homes but who would benefit from having a period of in-patient or day hospital care. In many cases, this will bring the added benefit of respite to the carer.

In these cases the health needs of the person receiving respite often (but not always) require it to be provided in a health care setting. NHS Boards should review local guidelines on responsibility for continuing care and/or respite to ensure that it meets these requirements.

Local authorities retain the responsibility to decide whether or not they will develop specific respite strategies or include their planning for respite in wider Carers Strategies, Community Care Plans, Integrated Children Services Plans or plans for specific groups of service-users. However, where separate strategies are developed, it is important for these to identify any opportunities for coordinated effort and joint working.

Types of Respite

The Guidance then discusses different types of respite and the different agencies that can provide respite.

The importance of personalisation in ensuring that respite has a positive outcome for service users and carers is highlighted and how this can be achieved by making service users and carers aware of their options and by building in as much flexibility as possible to adjust provision to individuals' needs.

The NHS

The role of the NHS in providing respite is noted. NHS Boards currently provide a range of services for patients/users that can also have the benefit of providing respite, despite that not being their primary purpose. These can include day services for people with a learning disability, a mental health problem or a physical disability; and day hospitals and assessment services for frail older people and older people with mental health problems. In most cases, access to these services will be regular and frequent as part of the planned care programme for the service user. This enhances the respite aspect since it allows the carer to plan ahead.

NHS Boards are advised to review how their services, including equipment, can support respite outwith NHS settings by meeting the continuing healthcare needs of the person receiving respite. For example, there is already a system for providing renal dialysis for patients on holiday within the UK and there are also examples of NHS Boards jointly funding respite services with local authorities in order to ensure that all the needs of the person receiving respite are met.

Planned and Emergency Respite

The effectiveness of planned scheduled respite and the need to plan for access to emergency respite is noted.

Planned, scheduled respite is an effective way of sustaining caring, helping people to remain in the community. It is most effective if used as an early intervention (preventing crises) and is regular and flexible.

However, it is important for people to have access to emergency respite, where a carer needs an urgent break. This can be to respond to or prevent a crisis, possibly to protect individuals or carers who are at risk. For example due to ill health of the carer, a deterioration in the health of the person they are looking after, or to respond to a crisis such as a bereavement. Services will need to be available at short notice, with the duration unknown, but limited.

Choice and Flexibility

Choice and flexibility are seen as of particular importance in the Guidance. Whilst the traditional model of respite provided in residential care home and day care settings will be appropriate for some, the benefit of being able to select from a wider variety of alternative options to satisfy different needs and circumstances, which may change over time.

The aim should be to provide service users and carers with greater choice and flexibility to determine, how, where and when their services are provided. Inevitably there will be limits to the extent to which every service can be individually tailored, but carers and service users have identified certain factors that are particularly important

- access to respite and short breaks in different settings;
- the option to have a break with or without the cared for person;
- access to respite at different times of the day/week;
- a choice in the length of break;
- flexibility over when respite is arranged; and
- confidence in the quality of care provided.

Increasing the range and flexibility of short break services should be central to local strategic planning, moving away from an over reliance on care home and day care services.

Direct payments can help deliver greater flexibility, choice and control over their respite arrangements. The money provided to meet assessed needs may be used for a short break in a traditional residential setting or alternative models - for example, to pay for a personal assistant to accompany a user on a holiday break, (with or without the carer), or for children to have a short break with a specialist care worker. This type of model can enable all parties to enjoy a family holiday.

Information

The Guidance then focuses on the need for easy access to information to help carers and service users decide about the respite services and support that would be best for them. Information should cover the full range of services available; how to access services; assessment procedures; charging policies or eligibility criteria that apply and where to go for more detailed guidance and support. More detailed information on respite should be available and carers and service users given the opportunity to discuss their particular needs, what they want from a respite break e.g. a regular break to spend time with friends and, how respite can help this happen. Health and social care professionals will need to be proactively involved in informing carers and service users about their

respite options. To do this effectively they will need a good knowledge of the services available and how to access further support.

There are other sources of information on respite including respite bureaux, national and local voluntary organisations.

Access to Services / Eligibility

The Guidance identifies that strategic planning will include decisions about provision and the criteria for accessing respite. However, authorities should involve service users and carers to be involved in the development and review of eligibility criteria and priorities and for all parties to understand these and the respite options available. Partnerships must publish clear eligibility criteria for support based on the outcome of assessments.

Both planned and emergency respite provision should be:

- Focused on prevention - designed to help individuals remain at home, sustaining caring relationships and preventing crises;
- Available for those most at risk, such as:
 - carers who themselves suffer from ill health or disabilities;
 - those with the most intensive caring responsibilities, caring for people with long term conditions which are fluctuating or deteriorating;
 - older carers;
 - young carers;
 - co-resident carers;
 - carers of children or adults with unpredictable or challenging behaviour, such as people who misuse substances and people with mental illness or dementia;
 - those caring for a long time;
 - carers of people with a terminal illness; and
 - carers with multiple caring roles.
- Designed to enable carers to remain in employment, if they wish to do so.

Charging

Charging for respite is discussed in the Guidance noting that separate charging arrangements apply for respite provision in residential care and other settings, but that local authorities have significant discretion on charging for respite care in both cases. Charges made to adult service users should not extend to their families or carers.

Partnerships are advised that, when considering charging policies, it is necessary to have regard to the wider longer-term effects. In line with the principle of working with carers as partners in the provision of care, cumbersome assessment of ability to pay, and charging policies which discourage the use of effective respite services are not in the best interests of users or carers or of the effective use of local authority resources. Poor

uptake of respite which increases the burden on carers can lead to caring relationships breaking down and a subsequent need for more expensive services such as permanent residential care.

Next Steps

The public consultation on the draft guidance for respite is now underway. To add your voice:

- Complete the questionnaire (also available online at www.carerscotland.org) and include your views in Carers Scotland's response to the Scottish Government.

A full copy of this response will be available online www.carerscotland.org. You can also request a copy of this response by completing the relevant section on the questionnaire or by contacting Fiona Collie at Carers Scotland on 0141 221 9141 email: fiona.collie@carerscotland.org

**Carers Scotland
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Indicators of Good Respite Care

Particular indicators of good respite care are that it is:

- based on thorough assessment and on-going review,
- appropriate to the needs and circumstances of the carer,
- appropriate for the age, culture, and level of need of the care recipient,
- able to maintain or improve the well-being of the care recipient,
- delivered by appropriately trained and caring staff,
- affordable, and
- reliable.

Personalised Respite - Examples of good practice

This annex offers guidance on the variety of approaches that can be taken to planning and delivering respite and the different outcomes (although it does not provide a comprehensive list). Respite occurs in a range of contexts and many service users and carers will need access to different types of respite and short-term breaks to meet different purposes and needs, possibly in combination with other community care services. It is important to stress the value of involving the carer and care recipient in determining their goals and outcomes for the short break. Evidence suggests that respite 'fails' when carers and care recipients have little control or influence.

Breaks in a care home

Although there is evidence of many people being uncomfortable with taking up a respite place in a care home, some will be happier to try this type of break if they can visit beforehand to see the facilities and meet the staff and make any special arrangements for the individual such as arrangements to host daily visitors during a week's stay. For some, however, the change of routine and environment may be too much, resulting in anxiety and confusion. Other forms of break may be more suitable.

Flexible booking of care home respite

Giving more control to those needing respite can improve choice and make better use of resources. For example, one local authority has booked a respite bed for people with dementia for the year in an independent care home. Families are allotted a number of nights of respite, up to four weeks, and enabled to book time as they wish with the home manager. People now have more control over their respite arrangements and can negotiate changes directly with the manager, rather than going through busy social workers. In the first year of this arrangement, the respite bed was used every night, a big improvement on previous years.

Community-based activities for adults with a learning disability (and others)

Community-based activities for adults with a learning disability can promote independence while providing an effective alternative to traditional, building-based respite. Successful services offer a variety of regular activities such as sport and leisure activities and educational courses and seek to match staff to clients with similar interests.

Breaks for young carers

Respite can be vital in preventing young carers becoming excluded by allowing them time with friends or peers to participate in social and leisure activities, or time for themselves. These opportunities are essential to promoting young carers' health and wellbeing.

Young carers can benefit greatly from carefully planned breaks. These should be person-centred and as flexible as possible offering a range of options to ensure that the young person is able to have a positive break from their caring responsibilities. Young carers are likely to be unfamiliar with the term respite and therefore some practical examples should be given to aid their understanding and allay any anxieties they may have about the service. Young carer respite should aim to improve health and well-being; reduce social exclusion; provide choices and empower young carers, leading to the following measurable outcomes:

- The young carer had a choice in determining the way respite was delivered.
- The young carer had the opportunity to participate in mainstream groups or activities.
- The young carer is able to attend a dedicated young carers service, residential trips or activity breaks.

Breaks in the home of another individual or family

These breaks are sometimes referred to as 'Shared Care', where children and young people are concerned, or 'Adult Placements', where clients are adults. The service is essentially the same involving specially recruited and trained individuals who are able to offer breaks in their own home. The 'homely' environment is an attractive feature of this form of break, plus the opportunity to build longer term relationships between host families, the carer and the care recipient.

- National Association of Adult Placement Services
- Shared Care Network
- The Fostering Network Scotland

Breaks at home

Regular, weekly short breaks at home are the preferred respite option for many people. 'In Home' breaks can be provided through sitter services or by personal assistants taking over caring responsibilities for a short period. The familiar surroundings can reduce feelings of anxiety and confusion and offer opportunities to tailor activities to the individual preferences of the care recipient. Services are particularly effective when they can be flexible, allowing those receiving the service to negotiate with the providing agency to adjust times to suit particular circumstances. Carers and service users also benefit from consistency, allowing them to get to know people over a long period. Befriending services can enable care recipients to leave the home and take part in social and leisure activities, promoting self esteem and confidence. However, breaks at home might not suit the carer where the purpose of the break is to provide them with time at home, free from any caring responsibilities, to rest and recover or spend time with other family members.

- Crossroads Caring Scotland
- Befriending Scotland

Providing equipment or adaptations to facilitate respite

Providing minor equipment can be invaluable to help facilitate a short break in the home of family or friends. For example, providing bed blocks, a raised chair and toilet seat could make an older person with mobility problems

much more comfortable about staying with someone if they knew they would be able to get in and out of chairs and bed easily and visit the toilet unaided.

Equally, for carers and cared for people living together, equipment such as an emergency alarm can make it safer for the person to remain at home alone for short periods. This can also be invaluable in enabling the carer to re-join regular activities outwith the home.

A further example would be changes such as ramps or door widening to accommodate a wheelchair in the home of a foster carer, to help enable respite care for a disabled child.

Involving service users and carers in respite planning

It is clearly good practice for those likely to use services to be involved in planning. For example, a group of service users, carers, health and social work reviewed what respite would be needed to respond to the closure of a particular NHS respite facility. In this case, more short holiday breaks were identified as the priority. A local provider of residential respite was keen to develop this service in the form of a caravan at a nearby holiday park. Because this was what carers and service users wanted, the facility has proved popular and is well used.

Respite in Supported housing

Residential respite in a single tenancy can provide a successful respite model where people, often with very complex physical needs, can be supported by individualised support staff to enjoy community facilities or just a rest.

Day care

Day-care covers planned services provided outside the home of the care recipient, not involving overnight stays. The extent to which traditional day-care services provide 'personalised respite breaks' has been the subject of much discussion. Many carers view day-care as a basic entitlement and that short breaks and respite services should be provided over and above this level of provision. However, there is no reason why day-care should not be considered as respite when the service is carefully designed to deliver this outcome, and meets the agreed needs of both the carer and care recipient. The duration, timing and accessibility of the service are important factors in this regard, alongside the opportunity for activities which provide for personal and social development.

Self-directed support for respite

Self-directed support (through direct payments) is a proven way for people to have a range of respite and short break experiences both within their own homes and at holiday destinations of their choice (see Holiday breaks).

Holiday breaks

The holiday break gives access to mainstream holiday provision through the availability of additional support, specialist providers or access to adapted holiday accommodation. Holiday breaks can provide social stimulation, new activities and being with different company in new environments.

The carer and cared for person can take a holiday break together or apart, depending on the purpose of the break. Breaks together offer an opportunity to escape the daily routine and to enjoy 'normal' experiences together, perhaps as a family. A personal assistant or companion might accompany them to provide additional support and to relieve the carer of some of the caring responsibilities.