

Consultation on Respite Care Guidance

Covering Letter

Primary and Community Care Directorate

Community Care Division

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To: See attached list

10 October 2007

Dear Consultee

Consultation on Respite Care Guidance

I am writing to invite your views on proposed new guidance on respite care.

Background

This draft guidance will update and replace guidance issued in 1996. It has been developed by a Government-led task group, made up of local authorities, voluntary organisations, regulators and the NHS.

The consultation period starts today, 10 October and will run for 14 weeks, with a final deadline for responses of 16 January 2008. Its main purpose is to 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 respite planning;
- shifting the balance towards preventative support; and
- personalising support to improve outcomes both for carers and those with care needs.

Consultation documents

The following documents relating to this consultation can be found on the Scottish Government website:

<http://www.scotland.gov.uk/Consultations/Current>

- This consultation letter
- Draft guidance on respite care
- Respite Task Group membership list
- List of consultees
- Respondent Information Form
- The Scottish Government Consultation Process

List of consultees

We have tried to cover all relevant interests. If you feel another party would benefit from seeing this consultation then please let Julie Wotherspoon know or pass on the consultation details.

What consultees are invited to do

You are welcome to comment on all aspects of the draft guidance but there are some particular issues on which we would value your input:

- What are the main strengths and weaknesses of the draft guidance?
- What if anything is missing?
- Is the terminology clear? The guidance mainly uses the term 'respite' but 'break' is also used, with both terms referring to situations where a short break is needed - either where there is a carer looking after someone or where a service user has no carer.
- Strategic Planning - Does the draft guidance cover the most important factors in relation to the strategic planning of respite services?
- Information Provision - Does the guidance cover the main aspects of information provision relating to respite? Are there additional examples of good practice which would be valuable to include?
- Eligibility - Are the suggested criteria and risk factors relevant and comprehensive?
- Annexe A - Indicators of good respite - Is the list relevant and comprehensive?
- Annexe B - Good practice - Are the examples relevant and useful? Can you suggest similar examples?
- Annex C - Respite needs of specific groups - Again, are those in the draft relevant and useful? Can you provide similar details for the other groups listed?

Where possible please provide explanation and examples to support comments made.

Responding to this consultation paper

As outlined above written responses are invited by 16 January, or earlier if possible. **Please send your response to:**

julie.wotherspoon@scotland.gsi.gov.uk

or

Julie Wotherspoon
Scottish Government
Primary and Community Care Directorate
Community Care Division
Room 2.E.R
St. Andrew's House
Regent Road
Edinburgh EH1 3DG

If you need us to print out and send you a copy of the consultation, or if you have any queries please contact Julie Wotherspoon or me at the above address or on 0131 244 5488 or 244 3503.

Please indicate in your response which questions or paragraphs of the consultation paper you are responding to as this will aid our analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at <http://www.scotland.gov.uk/consultations> . You can telephone Freephone 0800 77 1234 to find out where your nearest public internet access point is.

The Scottish Government now has an email alert system for consultations (SEconsult: <http://www.scotland.gov.uk/consultations>). This system allows individuals and organisations to register and receive a weekly email containing details of all new consultations (including web links). It complements, but in no way replaces Scottish Government distribution lists, and is designed to allow stakeholders to keep up to date with all consultation activity, and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register.

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the attached **Respondent Information Form** as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential, and will treat it accordingly.

All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Where respondents have given permission for their response to be made public (see the attached Respondent Information Form), these will be made available to the public in the Scottish Government Library and on the Scottish Government consultation web pages by 13 February 2008. We will check all responses where agreement to publish has been given for any potentially defamatory material before logging them in the library or placing them on the website. You can make arrangements to view responses by contacting the Scottish Government Library on 0131 244 4552. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next ?

Following the closing date, all responses will be analysed and considered with the respite Task Group before the guidance is finalised

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the address above.

Thank you for your help.

Yours sincerely
Peter Stapleton

Primary and Community Care Directorate
Community Care Division

DRAFT RESPITE GUIDANCE- SEPTEMBER 2007

Local Authority Directors of Social Work
Local Authority Directors of Children Services
Copy to Local Authority Chief Executives
Convention of Scottish Local Authorities
Local Authority Directors of Finance
Care Commission
LA Directors of Education
Association of Directors of Social Work
NHS Board Chief Executives
Association of Directors of Education in Scotland
Appropriate Voluntary Organisations

GUIDANCE ON RESPITE CARE

Summary

1. This guidance provides advice to adult Community Care Partnerships and to agencies engaged in children services on the planning and delivery of respite care. It should also be of interest to other individuals and organisations involved in social care. 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.

2. This guidance replaces *Scottish Office Circular SWSG 10/96*¹. Its main purpose is to 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 respite planning;
- shifting the balance towards preventative support; and
- personalising support to improve outcomes both for carers and those with care needs.

3. These themes are important aspects of the Scottish Government's overall policy direction for both health and social care services, in line with the Kerr Report *Building a Health Service fit for the Future* (2005)², *Changing Lives* (2006)³ and the Care 21 Report *The Future of Unpaid Care in Scotland* (2005)⁴. Personalisation of services and improving outcomes are also consistent with the Executive's priorities for services for children and young people described in the *Getting it right for every child* programme and in guidance on integrated services planning and quality improvement.

Action and expected outcomes

4. Recipients should use this guidance to update their strategic planning of respite services and their Local Improvement Targets for community care services. As a consequence, we would expect to see:

- strategic approaches to local planning, delivery and evaluation of respite and short breaks;
- carer and service user involvement in determining the shape, direction and level of provision of local respite and short break services;
- greater choice, flexibility and equity in the provision of services; and

- carers and service users feeling supported by the respite and short break services provided (linked to proposed National Outcome Measures).

SCOTTISH EXECUTIVE COMMUNITY CARE CIRCULAR CCD/XXX

DRAFT GUIDANCE ON RESPITE CARE

Introduction

Definition⁵

1. Respite (sometimes referred to as short breaks) 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 ⁶.

2. Some forms of day care may also be seen as within the definition of respite (Annex B) ⁷. 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.

3. 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.

4. In this guidance, the term 'respite' is mainly used but 'break' is also included. Unless specifically described in the text, both terms refer to situations where a short break is needed, both where there is a carer looking after someone and where a service user has no carer.

Evidence of value of respite and purpose of respite

5. The principal evidence of the value of respite care is based on the perceptions of carers, discussed in reviews of studies such as *Making a Break*⁸ and confirmed by the 'Voices of Carers' survey which formed part of the evidence base of the Care 21 Report *The future of unpaid care in Scotland*⁹. 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.

6. 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.

Purpose of guidance

7. This guidance is to assist partnerships to meet their responsibilities to plan and deliver respite care but it is also designed to be helpful to other interested parties including service users, carers and service providers. The Executive is promoting the development of strategic approaches to expand and improve respite services through this guidance. Community Care Partnerships should also use it to update their Local Improvement Targets for respite.

Policy Context

8. The importance of supporting carers and enabling people to live independently at home are both well established aspects of the Scottish Executive's approach to health and social care. We recognise the crucial contribution which unpaid carers make to Scottish society and that unpaid care is likely to grow in importance. The *Strategy for Carers in Scotland*¹⁰ (1999) has been refocused through the Care 21 Report - *The future of unpaid care in Scotland*¹¹ (2005) and the Executive's Response¹² (2006). The response focuses on four priority areas, including respite and carer health.

9. These documents, as well as the Kerr Report *Building a Health Service fit for the Future*¹³ (2005) and *Changing Lives*¹⁴ (2006), contain a number of themes which are fundamental to this guidance:

- working with carers as partners in providing care;
- joint-working;
- shifting the balance of care towards preventative support and enabling self care; and
- personalisation of support.

10. Personalisation of services and improving outcomes are also important aspects of the Executive's priorities for services for children and young people described in *Getting it right for every child* and in guidance on integrated services planning and quality improvement.

Strategic Planning

11. Responsibility for the planning and delivery of care services including respite lies with Community Care Partnerships and with the local partnerships which plan, design and deliver services for children and young people¹⁵. Despite this being clear in the 1996 respite guidance, there is still considerable variation in the extent to which authorities have planned their respite services. Partnerships 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.

12. 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 include, as well as the points above, 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.

13. Executive guidance on *Integrated children's services planning* includes young carers within a list of examples of children in need. The *Quality Improvement Framework for Integrated Services for Children* also refers to respite care (under the "Nurtured" heading). The *Getting it right for every child* programme builds on this approach by placing the needs of the child at the centre of service delivery, regardless of what these needs might be, and encourages local agencies to work together to meet needs through individualised plans. Local authorities have a duty under the Children (Scotland) Act 1995, to safeguard and promote the interests of children in need, including disabled children and young carers. Also to assess the support needs of children and, where appropriate, their carers, which can include respite.

14. The Arrangements to Look After Children (Scotland) Regulations 1996 applies conditions (including regular review) to short-term placements of children where:

- (a) all the placements occur within a period which does not exceed one year;
- (b) no single placement is for a duration of more than 4 weeks; and
- (c) the total duration of the placements does not exceed 120 days.

15. National Care Standards will also apply to the provision of such placements. 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.

16. Joint planning needs to recognise not just the intended direction but also any shifts in resourcing between agencies in the way services are provided, and the implications that has for them. Short-term care (respite) previously provided by the NHS for people whose needs are predominately for social care is increasingly being commissioned by local authorities. It is important that partnerships plan such changes together, with the involvement of users and carers. NHS Boards and local authorities should therefore agree their complementary responsibilities for short-term health care respite and social respite care, both planned and emergency. In particular, 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.

17. 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. (See also paras 20 and 21 below on other NHS responsibilities.)

18. It is for local partnerships to decide whether to develop specific respite strategies or to include their strategic planning 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

19. As noted above, the evidence shows that personalisation is important in ensuring respite has a positive outcome for both those with care needs and carers. This can be achieved by making sure that those with care needs and carers are aware of their options and by building in as much flexibility as possible to adjust provision to individuals' needs. Annex A sets out the main indicators of good respite. The main types of respite are set out in the definition of respite services above and Annex B provides examples of good practice in providing personalised respite.

20. NHS Boards 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.

21. NHS Boards should 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 well established system for providing renal dialysis for patients on holiday within the UK and there are also many local arrangements where NHS community services support other agencies that provide respite. 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.

22. 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) is regular and flexible.

23. 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.

24. The more traditional model of respite provided in residential care home and day care settings will be appropriate for some but carers and service users benefit from being able to select from a wider variety of alternative options to satisfy different needs and circumstances, which may change over time.

25. 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 important¹⁶¹⁷:

- 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.

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

27. Self-directed support provides a valuable option for people to have greater flexibility, choice and control over their respite arrangements. The money provided to meet their 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. (Limits on the length of stay purchased in residential accommodation are set out in national guidance¹⁸.)

Information

28. Easy access to information is very important to enable both carers and service users to 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.

29. The mechanisms for communicating this information should be set out within local strategies for involving and engaging with carers and service users, including Carer Information Strategies¹⁹. In many areas this will include advice from local carer centres. Particular attention should be paid to targeting information to under represented groups such as black and minority ethnic communities. 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.

30. More detailed information on respite options should be easily accessible and carers and service users given the opportunity to discuss their particular needs, identifying the outcomes they want and how respite might help achieve them. This could form part of the

care/carer assessment and review (but other means of accessing this support and guidance should be available).

31. It is important that carers and services users understand that assessment is the start of an ongoing process, where any service provided is regularly reviewed. This will ensure that the care package, including respite care, continues to deliver the agreed outcomes and responds to the carer and care recipient's changing needs and circumstances.

32. Respite Bureaux offer a valuable "One Stop Shop" approach to providing information and access to a variety of respite breaks. Bureaux aim to make the process of accessing respite as streamlined and user friendly as possible working from information obtained from care/carer assessments. Because respite is their speciality, bureaux are successful in identifying flexible breaks which are tailored to the needs of the individual and their carers.

33. Many national charitable organisations publish information and advice on short break and respite services catering for their particular client groups, and some offer specialist respite facilities or short break opportunities. Shared Care Scotland provides a central source of information on these services along with advice on policy and practice, practitioner networks and learning events²⁰.

Access to Services / Eligibility

34. As noted above, respite is crucial in enabling many carers and service users to protect their health, prevent crises and continue living at home. Decisions about provision will form a central element of local strategic planning for respite. It is clearly good practice for 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.

35. Partnerships should therefore 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.

36. Particular risks and characteristics to be taken into account for many of these groups are explained in more detail at Annex C.

Monitoring, Quality Assurance and Regulation

37. As noted above, effective service planning needs to be informed by a clear understanding of the range and volume of existing provision, its strengths, weaknesses and gaps, based on local needs including feedback from service users and carers. Local partnerships are already required to report to Audit Scotland annually on performance indicators for respite provision for children, adults and older people. Community Care Partnerships should also set and report locally on Local Improvement Targets for respite and report on [planned] National Outcome Measures including those on carer assessments and carers feeling supported to continue caring.

38. Where respite is offered in care services defined under the Regulation of Care (Scotland) Act 2001 (e.g. care homes or day care services), these are regulated by the Scottish Commission for the Regulation of Care ('the Care Commission'). The Care Commission regulates these services under the Act (and regulations), taking account of the appropriate National Care Standards (NCS). In addition to service specific NCS, the Standards for Short Breaks and Respite Care ²¹ apply to respite offered through any regulated service. The standards address the service user's needs and the needs of their carer or family (or both). They cover some services that rely on volunteers. The respite standards are designed to achieve a balance in which service quality is guaranteed and a range of models can be developed.

39. Some services to the person for whom the respite service is being primarily provided may incidentally provide the carer with a break. These indirect sources of support are not included in the scope of the respite standards.

Charging

40. Separate charging arrangements apply for respite provision in residential care and other settings, but 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.

41. For the first eight weeks in a care home, local authorities do not have to formally assess a person's ability to contribute to the cost. During that period the authority should only charge what it considers reasonable for the resident to pay, having regard to his or her resources and financial obligations, particularly for maintaining his or her own home. The basis for any charge should be made clear. After eight weeks of continuous care authorities must charge the resident at the standard rate for the accommodation and carry out a formal assessment of ability to pay, in line with the regulations. The assessment should still take into account the temporary nature of the stay. The repeal of the liable relatives rule [will mean] that local authorities can no longer ask a spouse to contribute to a person's care home fees ²².

42. Charging for other respite accommodation, such as holiday breaks or other supported accommodation, will vary according to its management and provision.

43. Local authorities have discretionary powers to charge for non-residential care services, excluding those classed as free personal care for those aged 65+. General guidance on adult home care charging was issued in 1997 ²³ and COSLA issued guidance in 2006 to improve consistency in local charging policy ²⁴. As for residential care, authorities should not charge more than an individual could reasonably afford to pay. The basis for making any charge should be clear and made readily available on agreeing the service.

44. 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.

Scottish Executive
Primary and Community Care Directorate
Community Care Division
August 2007

Annex A: 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.

Annex B: 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.

Note: While this annex includes examples of good practice in a number of respite models, consultees are invited to suggest similar examples for other types of respite.

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 ²⁵

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.

Annex C: Respite needs of specific groups

Note: While this annex includes advice on the particular needs of a number of groups, consultees are invited to suggest similar advice for others such as:

- *older carers,*
- *people with mental health problems and their carers,*
- *co-resident carers,*
- *people with learning disabilities and their carers,*
- *carers/service users from black and minority ethnic communities*
- *people with autism spectrum disorders,*
- *people with profound and multiple disabilities.*

Those caring for a long time

Carers in a long term caring situation are often at risk due to the cumulative effects of long term caring on carers' health and wellbeing and may become isolated.

Adults living with older parent carers

For adults (e.g. with a learning disability) living with older parent carers, respite can be especially valuable in helping both parties to plan and prepare for the time when the carer will not be able to continue providing the same level of care.

Carers of disabled children

Caring for a disabled child, 24 hours a day can be very challenging for the child's family - physically, emotionally and often financially. Short breaks and building families' capacity to care can have positive benefits for both children and carers, helping to alleviate carer stress.

Carers of people with a terminal illness

In the case of palliative care, carers may require more regular breaks as they are also coping with the grieving process. There may also be a need for more specialised services.

Carers suffering stress

Consideration should be given to prioritising respite to allow carers to access services which will enhance their coping mechanisms and help them to develop support networks. For example, regular attendance at a carers support group, counselling or a carer training course.

Caring relationships under pressure

Respite can be particularly valuable where the caring situation is in danger of breaking down due to stress on family relationships caused by caring responsibilities. (Often counselling and additional support is needed to allow people to come to terms with changing relationships.)

Carers with multiple caring roles

Such situations are often stressful and there is often the tendency to look at each caring situation in isolation, without taking account of the cumulative effect.

Young carers

The range of caring roles undertaken by young people is as broad as the spectrum of specific groupings considered in this appendix. Young carers are *not* a sub-group of adult carers and have needs which are specific to each child or young person. When considering the respite and short-break needs of young carers attention must be given to the age of the child or young person, their abilities and strengths and the impact of their caring role on their life. The whole child must be central to any assessment and the impact of caring on their physical, social, educational, emotional, spiritual and psychological development understood. Young carers should be supported to take an active role in decisions about short breaks and respite.

Respite Task Group - Membership

Adam Rennie (Chair), Peter Stapleton, Jane Leask - Scottish Government
Claire Cairns, Coalition of Carers in Scotland
Yvonne Littlejohn, Mattie Crossley, Care Commission
Jack Ryan, Crossroads Caring Scotland
Martha Shortreed, Social Work Inspection Agency
David Small, NHSScotland
Don Williamson, Shared Care Scotland
Jackie Donnelly and Eddy Fraser, Association of Directors of Social Work
Fiona Collie, Carers Scotland
Mary Yates, Respite Sharing Practice Network

LIST OF CONSULTEES

Age Concern Scotland
Alzheimer Scotland
Arthritis Care Scotland
Association of Directors of Social Work
Association of Directors of Education in Scotland
BAAF Scotland
Barnardo's (Scotland)
Black and Minority Ethnic Elders Group
British Association of Social Workers
BUPA
Capability Scotland
Care Commission
Carers Scotland
Chest Heart and Stroke Scotland
Children 1st
Children in Scotland
Child Brain Injury Trust (Scotland)
Children's Hospice Association Scotland
Choices Community Care Services
Coalition of Carers in Scotland
Community Care Providers Scotland
Community Integrated Care
Contact a Family
Contact the Elderly in Scotland
Cornerstone Community Care
Convention of Scottish Local Authorities
Crossroads Scotland
CrossReach
Deaf Action
Deaf Connections
Deafblind Scotland
Dementia Services Development Centre
Depression Alliance
Down's Syndrome Scotland
Edinvar Community Care
ELCAP
Enable
Equal Opportunities Commission
Epilepsy Action Scotland

Glasgow Centre for Integrated Living
Guide Dogs for the Blind Association
Headway
Help the Aged
Leonard Cheshire Scotland
Local Authority Chief Executives
Local Authority Directors of Education
Local Authority Directors of Social Work
Lothian Centre for Integrated Living
Macmillan Cancer Relief
Manic Depression Fellowship
Mental Health Foundation Scotland
Mental Welfare Commission for Scotland
Minority Ethnic Carers of Older People Project
Momentum Scotland
Multiple Sclerosis Society Scotland
National Association of Special Education Needs
National Autistic Society
National Commission for Social Care
National Schizophrenia Fellowship (Scotland)
NCH Action for Children Scotland
NHS Boards Chief Executives
Nuffield Centre for Community Care
PAIN Association Scotland
PAMIS
Penumbra
People First
Princess Royal Trust for Carers, Scotland
Quarriers
Richmond Fellowship Scotland
Royal National Institute for the Blind
RNID Scotland
Scottish Association for Mental Health
Scottish Care
Scottish Churses Parliamentary Office
Scottish Community Care Forum
Scottish Consortium for Learning Disability
Scottish Council for Deafness
Scottish Development Centre for Mental Health
Scottish Downs Syndrome Association
Scottish Huntington's Association
Scottish Motor Neurone Disease Association
Scottish Pensioners Forum
Scottish Research Assistants Employment Network
Scottish Society for Autism
Scottish Spina Bifida Association
Scottish Young Carers Services Alliance
Scottish Youth Parliament
SENSE Scotland
Shared Care Scotland
Social Care Association
Spinal Injuries Scotland
The Fostering Network Scotland
The Thistle Foundation
Values into Action

Waverley Trust
Who Cares?
Young Scot

RESPONDENT INFORMATION FORM

Please complete the details below and attach it with your response. This will help ensure we handle your response appropriately:

Name:

Postal Address:

Consultation title:

1. Are you responding as: (please tick one box)

(a) an Individual (go to 2a/b)

(b) on behalf of a group or organisation (go to 2c)

2a.INDIVIDUALS:

Do you agree to your response being made available to the public (in SG library and/or on SG website)?

Yes (go to 2b below) No, not at all

2b. Where confidentiality is not requested, we will make your response available to the public on the following basis (please tick one of the following boxes)

Yes, make my response, name and address all available

Yes, make my response available, but not my name or address

Yes, make my response and name available, but not my address

2c ON BEHALF OF GROUPS OR ORGANISATIONS:

Your name and address as respondents **will be** made available to the public (in the SG library and/or on SG website). Are you content for your response to be made available also?

Yes No

SHARING RESPONSES/FUTURE ENGAGEMENT

3. We will share your response internally with other SG policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Government

to contact you again in the future in relation to this consultation response?

Yes No

THE SCOTTISH GOVERNMENT CONSULTATION PROCESS

Consultation is an essential and important aspect of Scottish Government working methods. Given the wide-ranging areas of work of the Scottish Government, there are many varied types of consultation. However, in general, Scottish Government consultation exercises aim to provide opportunities for all those who wish to express their opinions on a proposed area of work to do so in ways which will inform and enhance that work.

The Scottish Government encourages consultation that is thorough, effective and appropriate to the issue under consideration and the nature of the target audience. Consultation exercises take account of a wide range of factors, and no two exercises are likely to be the same.

Typically Scottish Government consultations involve a written paper inviting answers to specific questions or more general views about the material presented. Written papers are distributed to organisations and individuals with an interest in the issue, and they are also placed on the Scottish Government web site enabling a wider audience to access the paper and submit their responses²⁶. Consultation exercises may also involve seeking views in a number of different ways, such as through public meetings, focus groups or questionnaire exercises. Copies of all the written responses received to a consultation exercise (except those where the individual or organisation requested confidentiality) are placed in the Scottish Government library at Saughton House, Edinburgh (K Spur, Saughton House, Broomhouse Drive, Edinburgh, EH11 3XD, telephone 0131 244 4565).

All Scottish Government consultation papers and related publications (eg, analysis of response reports) can be accessed at: Scottish Government consultations (<http://www.scotland.gov.uk/consultations>)

The views and suggestions detailed in consultation responses are analysed and used as part of the decision making process, along with a range of other available information and evidence. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

Final decisions on the issues under consideration will also take account of a range of other factors, including other available information and research evidence.

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.

Footnotes

1. <http://www.scotland.gov.uk/library/swsg/index-f/c161.htm>
2. <http://www.scotland.gov.uk/Publications/2005/05/23141307/13104>
3. <http://www.scotland.gov.uk/Publications/2006/02/02094408/0>
4. <http://www.scotland.gov.uk/Publications/2006/02/28094157/0>
5. Developed from the National Care Standards for Short Breaks and Respite Care Services for Adults - <http://www.scotland.gov.uk/Resource/Doc/69582/0017383.pdf>
6. Self directed support (historically known as direct payments) enables greater choice and control over how a person's social care needs are met by directing and/or managing support arrangements themselves. Individuals are able to purchase support from a care provider or agency, a personal assistant (PA) or from a neighbouring local authority.
7. Audit Scotland Performance Indicators on respite only include day care if it is explicitly provided to give a carer a break.
8. *Making a Break: Developing methods for measuring the impact of respite services* (2004). Chesson RA and Westwood CE Aberdeen: The Robert Gordon University.
9. *The future of unpaid care in Scotland* (2005). Report by Care 21 Unit and Office for Public Management for the Scottish Executive.
<http://www.scotland.gov.uk/Publications/2006/02/28094157/0>
10. <http://www.scotland.gov.uk/library2/doc10/carerstrategy.asp>
11. <http://www.scotland.gov.uk/Publications/2006/02/28094157/0>
12. <http://www.scotland.gov.uk/Publications/2006/04/20103316/0>
13. <http://www.scotland.gov.uk/Publications/2005/05/23141307/13104>
14. <http://www.scotland.gov.uk/Publications/2006/02/02094408/0>
15. Separate statutory authority exists for respite provided to children and to adults. Section 25(2) of the Children (Scotland) Act 1995 states that local authorities may provide accommodation for any child if they consider it would promote his welfare, notwithstanding that he or she already has suitable accommodation. In respect of adults, section 12(1) of the Social Work (Scotland) Act 1968 states that it shall be the duty of local authorities to provide assistance, including residential accommodation, as they may consider suitable. Section 12A of that Act provides that the local authorities shall make an assessment of the needs of the person, and then decide whether their needs call for the provision of services. Regulation 10(2)(c) of the Community Health Partnerships (Scotland) Regulations 2004 (SSI 2004/386) provides that schemes of establishment shall set out the services to be provided by each CHP. Statutory Guidance, provided under section 4B(7) of the National Health Service (Scotland) Act 1978, on the functions of Community Health Partnerships, states at para. 23 that CHPs will manage and provide respite or short break services for all client groups.
16. *Review of Respite Services and Short Breaks from Caring for People with Dementia and their Carers*, National Co-ordinating Centre for NHS Service Delivery and Organisation, Arksey, H et al (2004)
17. *Making a Break: Developing methods for measuring the impact of respite services* (2004). Chesson RA and Westwood CE Aberdeen: The Robert Gordon University
18. <http://www.scotland.gov.uk/Resource/Doc/181224/0051499.pdf>
19. http://www.sehd.scot.nhs.uk/mels/HDL2006_22.pdf
20. <http://www.sharedcarescotland.com/>
21. <http://www.scotland.gov.uk/Resource/Doc/69582/0017383.pdf>
22. http://www.sehd.scot.nhs.uk/publications/CC2007_04.pdf [link to *Liable Relatives repeal guidance when issued*]
23. <http://www.scotland.gov.uk/library/swsg/index-f/c172.htm>
24. <http://www.cosla.gov.uk/attachments/execgroups/sh/shchargingguidance2006.doc>
25. Reference to forthcoming guidance from review of equipment and adaptations guidance.
26. <http://www.scotland.gov.uk/consultations>