



Picking up the pieces

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Supporting Carers
with Emergency Planning

September 2012



Foreword

I am pleased that we have been able to support ENABLE Scotland in carrying out a review of emergency (contingency/anticipatory) planning for carers in Scotland and in making recommendations on the way forward. This is an important piece of work which takes forward actions in the Carers Strategy, *Caring Together*.

Crucially, adult carers – and indeed young carers too – need to have peace of mind by knowing what arrangements will be put in place in the event of an emergency, either planned such as the carer going into hospital for planned treatment or unplanned such as the carer taking suddenly ill.

The need for emergency planning is certainly relevant for carers of adult children with learning disabilities. That is why we asked ENABLE Scotland to lead on the work. But in recognition that emergency planning applies across the board, ENABLE Scotland also worked with other organisations, including Alzheimer Scotland and the Scottish Young Carers Services Alliance. This is collaborative working in action.

I welcome the emphasis on carers taking control of their own arrangements for emergency planning through developing their own plans. This, combined with action by statutory and Third Sector agencies to support emergency planning, will help establish firm arrangements.

I am encouraged by the many good examples of emergency planning being taken forward by local authorities and others as highlighted in the report. I am also pleased that a number of Change Plan submissions for older people demonstrate that they are supporting carers of older people with emergency planning. However, the good practice needs to become the universal practice. For the Government's part, we will be embedding emergency planning within new guidance on the undertaking of Carer's Assessments. We will hold learning and sharing events to include emergency planning. We also look to our strategic partners to ensure that they work with carers and young carers on emergency planning.

Michael Matheson MSP
Minister for Public Health



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About ENABLE Scotland

ENABLE Scotland is a charitable organisation founded in 1954 by a group of parents of children with learning disabilities.

Its aims are:

- To ensure that people who have learning disabilities have the same choices and opportunities in life as everyone else;
- To undertake campaigns to ensure that people who have learning disabilities are regarded as equal members of society;
- To provide a range of person-centred services designed to ensure that people who have learning disabilities can live the life they want and actively participate in their community.

Please note that the information contained in this report is as accurate, current and complete as possible.

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Executive Summary

This report presents the findings of research carried out by ENABLE Scotland between April 2011 and April 2012 with the aim of improving knowledge and understanding of emergency planning for carers in Scotland, particularly within the wider context of Carer's Assessments.

The report has two main objectives:

1. To establish the provision of support to carers with emergency planning across all local authority areas, highlighting examples of good practice and producing recommendations based on the findings.
2. To explore the role of sibling carers in the emergency planning process.

The research focused on collecting information from stakeholders, including local authority areas, voluntary agencies, carers and carers' family members. As well as factual information, discussion events were held to capture personal experiences to obtain as full a picture of the current situation as possible.

Emergency Planning Provision

Overall, evidence suggests that local authority areas are refreshing or rewriting their Carers' Strategies and aligning their plans with the actions outlined in *Caring Together* and *Getting It Right For Young Carers, the Carers and Young Carers Strategy for Scotland 2010-2015*.

While the strategy represents a framework for action in relation to all carers, including young carers, a great deal of effort has focused on embedding carers' issues into key policy developments within health and social care in Scotland.

There is a key emphasis on multi and cross agency working and many references within *Caring Together* to the involvement of carers as key partners.

The research identifies many examples of good practice across Scotland.

Despite this increase in profile, however, current provision of emergency planning support services to carers across Scotland is piecemeal and inconsistent, with the levels of support offered to carers dependent on location rather than need and varying greatly in nature.

There are few specialist services that support carers to plan for an emergency and of those identified by the research, the majority are of short term duration, funded through initiatives such as the Big Lottery Fund or the Change Fund.

Carer's Assessments

Nationally the low uptake of Carer's Assessments (also known as Carer Support Plans) is recognised and there is much work being undertaken at local and national level to increase the quality and uptake of Carer's Assessments.

Within Carer's Assessments there is great variation in the information requested from the carer about his/her plans for an emergency. There is also variation in the action taken should a carer not have a plan for an emergency.

Carers

Most carers don't have a written plan for an emergency. In many cases, the main carer's expectations and wishes regarding an emergency situation have not been communicated to other family members and are known only to the carer. The very nature of an emergency situation means that all carers are at risk of the unexpected happening and need to have plans in place.

An emergency plan does not necessarily involve contributions from health or social work services. Rather, for most carers, it would be a preventative approach involving family and personal networks in the first instance.

However there are key groups of carers who are particularly at risk and taking a preventative approach to better identification and support for this group is required.

For many carers an emergency situation may be an indicator of a future crisis situation that needs a proactive approach. For example, the deterioration of the carer's health or the escalation of the cared-for person's needs.

Siblings

Siblings play a unique role in the care of brothers and sisters with support needs and being a family carer is a key consideration for most when planning their futures. There is currently little recognition of the importance of siblings as possible primary or secondary carers.

Summary of Recommendations

1. There is potential to integrate the development of emergency planning within many of the action points outlined in the Implementation Plan of *Caring Together* and *Getting It Right For Young Carers*, the *Carers and Young Carers Strategy for Scotland 2010-2015*.
2. Emergency planning for carers should also be considered within all current and future health and social care policies.
3. Emphasis on early intervention and preventative actions to avoid crisis situations should be the default position within all local authority areas.
4. The use of Carer Emergency Card Schemes or similar approaches should be actively promoted in all local authority areas with local authority areas working towards integrating existing or new resources such as Emergency Card Schemes with local emergency provision.
5. There should be a focus on improving the quality of Carer's Assessment to include better emergency planning.
6. Where carers identify the need for an emergency plan within a Carer's Assessment, support should be provided to ensure that the carer has a plan that will work for them.
7. Agencies engaging with carers should have knowledge of how to provide signposting or advice to carers on emergency planning.
8. Carers need support to address and manage their own emergency planning arrangements and there is a role for condition-specific organisations and the voluntary sector to help them do this through training and awareness raising.
9. Emergency planning must also link to future planning arrangements, particularly for those carers whose situations would put them and/or the cared-for person at risk.
10. Identification of carers at risk of a future emergency needs to be improved and health professionals such as GPs and hospital discharge teams, who are often the first line of contact, should be able to signpost carers, provide relevant information and discuss the issue with carers.
11. There should be a stronger role for health services in encouraging carers to make emergency plans.
12. Services should ensure that the unique caring role of siblings is recognised: furthermore, siblings should be involved in key discussions relating to the cared-for person, particularly in relation to planning for emergencies and longer term planning.

Background and Context

For some years, older carers of people with learning disabilities have reported their concerns to ENABLE Scotland about the lack of support available to help them plan for the point in the future when they become unable to care. Many of these carers experience anxiety and reduced peace of mind as a result.

ENABLE Scotland has raised awareness of this issue, both alone and in partnership with other organisations, by postcard campaigns, and by organising events which have given carers the opportunity to ask questions of politicians.

Caring Together and Getting It Right For Young Carers, the Carers and Young Carers Strategy for Scotland 2010-2015

The strategy sets out the Scottish Government's priorities for the provision of support to carers in Scotland that local authorities/health boards must act on.

All Action Points in the strategy focus on ensuring better outcomes for carers.

Carers will:

Have improved emotional and physical well-being.

Have increased carer confidence in managing the caring role.

Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring.

Not experience disadvantage or discrimination, including financial hardship as a result of caring.

Be involved in planning and shaping the services required for the service user and the support for themselves.

Young carers will be relieved of inappropriate caring roles and will be supported to be children and young people first and foremost.

Following the publication of *Caring Together* and *Getting It Right For Young Carers*, the *Carers and Young Carers Strategy for Scotland 2010-2015*, in November 2010 representatives from ENABLE Scotland met with Shona Robison MSP, the then Minister for Public Health and Sport, to ensure that the needs of older family carers of people with a learning disability were recognised.

Following this meeting, ENABLE Scotland submitted an application to the Scottish Government and was successful in securing funding to undertake this research, under Action Point 13.6 of the Implementation Plan aligned to *Caring Together* and *Getting It Right For Young Carers*, the *Carers and Young Carers Strategy for Scotland 2010-2015*:

"The Scottish Government will work with a range of partners to explore the potential to develop emergency respite and to support carers with emergency planning."

The Research Proposal

The aim of the proposed research was to support the development and promotion of preventative emergency planning within the wider context of Carer's Assessments.

This was to be achieved in two phases:

Phase 1 would scope the emergency planning tools and working policies available within local authority areas within the context of Carer's Assessments.

Phase 2 would research the experience of siblings of people with learning disabilities and what they can do to support the emergency planning process.

The Project Plan

Phase 1

Identify and engage appropriate local authorities and partners to participate in the Emergency Planning Steering Group.

Scope work in relation to emergency planning currently being developed, or already developed across local authority areas.

Hold a "Think Piece" event on emergency planning to capture input from appropriate agencies and carers.

Identify the benefits to local authorities of implementing emergency planning.

Phase 2

Identify siblings of people with learning disabilities through ENABLE Scotland services, membership and branches and through other professional networks.

Establish focus groups to discuss details and issues around emergency planning and future planning from the perspective of siblings.

Identify themes, issues and practicalities impacting on siblings and emergency planning.

Produce a report with recommendations.

Definition of Emergency Planning

Emergency Planning

For the purpose of this research and subsequent report an emergency has been defined as an illness, accident, personal crisis or event which unexpectedly, or at least at very short notice, results either in the carer being separated from the cared-for person on a short or long-term basis or in an escalation of the cared-for person's needs. It could include a family funeral, a transport delay, family illness, admission to hospital, last-minute doctor or dentist appointment or a personal accident affecting the carer. The purpose of emergency planning is twofold:

- Planning to lessen anxiety and increase confidence for carers;
- Identifying resources for an emergency where family members cannot be relied upon.

Carer's Emergency Plan

This is a carer's own personal plan of what should happen and who will help to make sure that the person they care for is safe and well in the event of an emergency happening.

Policy and Legislative Framework

Carer's Assessments

The Community Care and Health (Scotland) Act 2002 affirms that carers who provide or intend to provide a “substantial amount of care on a regular basis” are entitled to an assessment of their ability to provide or to continue to provide care (Carer's Assessment), independent of any assessment of the person they care for. Young carers under 16 have the same rights to assessment.

Who Should Carry out Carer's Assessments?

Local authorities have powers under Section 4 of the Social Work (Scotland) Act 1968 and Section 19 of the Children (Scotland) Act 1995 to involve other bodies or persons in helping them to carry out their functions, including voluntary bodies. The Single Shared Assessment and Carer's Assessments extend the opportunities to involve a range of staff and agencies in assessment, stressing the principle that the most appropriate professional should be responsible for carrying out the assessment, co-ordinating any other contributions, and identifying the support or resources needed.

National Minimum Information Standards

The Scottish Government has developed National Minimum Information Standards (NMIS) for adults, covering assessment, support planning and review. The purpose of the Standards is to promote good practice in the recording of information that is gathered for the purposes of assessment to be used in care management and to support standardisation of assessment practice and related activities.

The National Minimum Information Standards describe the subject matter that must be included without specifying exactly how it should be done or recorded. This leaves flexibility at local level as to how information standards are incorporated into local tools and guidance in an appropriate manner.

Minimum Standards for Carer's Assessment and Support

These include national minimum information standards for the identification of needs and support for carers (Carer's Assessment).

Minimum standards are listed under the following headings:

- a) Caring situation
- b) Carer responsibilities
- b) Health and wellbeing
- c) Life of your own
- d) Supporting the caring role

National Minimum Information Standards: Requirements for Carer's Assessments

The National Minimum Information Standards (NMIS) for Carer's Assessment suggest that Carer's Assessment should include information on determining whether the caring role is sustainable and should identify current and potential risks to the carer's health and wellbeing as a result of the caring role.

Key questions

Supporting the caring role

1. Are there any measures in place for emergency or crisis planning?
2. If yes, what are these measures?
3. If not, what would need to be done if an emergency arose?

The future (explore concerns and plans for the future)

1. Are there any potential changes in the future, which may affect your caring role?
2. If yes, what are these?
3. What can be done to address this?
4. What are your hopes and plans for the future?

Preliminary Research Phase

Following Scottish Government approval of the funding application in March 2011, a period of preliminary groundwork was undertaken to prepare for the commencement of Phase 1 of the research.

Methodology

Steering Group

A steering group of representatives from a variety of voluntary and statutory organisations was set up in April 2011 to monitor the progress of the research and to offer advice and guidance.

The organisations represented were:

Alzheimer Scotland

ENABLE Scotland

Glasgow City Council: Social Work

Minority Ethnic Carers Older People's Project (MECOPP)

Scottish Government: Unpaid Carers Policy Unit

Shared Care Scotland

South Lanarkshire Council: Social Work

The Steering Group met five times over the duration of the research exercise, which was between April 2011 and April 2012.

Desktop Research

During March and April 2011 a period of desktop research was carried out. Local authority websites and other sources of information were searched with two objectives:

- To identify the lead contact within each local authority area with responsibility for developing the local response to *Caring Together* and *Getting It Right For Young Carers, the Carers and Young Carers Strategy for Scotland 2010-2015*.
- To obtain information on local provision of emergency planning including copies of the local Carers Strategy and/or Carer's Assessments for reference, if available.

A significant challenge was experienced at this stage in identifying the named individual who could respond on behalf of the local authority area. As a result, local carers' centres were consulted to provide the required information, which involved additional time in this phase of research.

Preliminary Online Questionnaire

Having established the lead contacts, a preliminary electronic questionnaire containing 10 questions was sent to all 32 local authorities in Scotland in April 2011. See Appendix 1.

The main aim of the questionnaire was to find out:

- a) What was happening with local carers strategies in terms of their duration and priorities;
- b) How emergency planning linked with Carer's Assessments;
- c) What services were available to help carers to plan for an emergency;
- d) What priority should be given to emergency planning for carers.

From the 32 areas, a 50% response rate was achieved by the deadline of June 2011. These 16 returns provided a snapshot of the situation across Scotland.

Findings from Preliminary Phase

- a) Preliminary findings suggested that local authority areas were refreshing or rewriting their Carers' Strategies and aligning their plans with the actions outlined in the Monitoring and Implementation Plan of *Caring Together* and *Getting It Right For Young Carers, the Carers and Young Carers Strategy for Scotland 2010-2015*. Key themes included multi and cross agency working and the involvement of carers as key partners.
- b) Two thirds of questionnaire respondents indicated that their local authority areas carried out assessments on their own. The remaining one third indicated that they carried out assessments with a partner or partners, in most cases carers' centres. Most responses indicated that a self-assessment protocol for carers existed with online resources being developed in other areas.
- c) Most questionnaire respondents indicated that their local authority area would actively support carers to develop a plan. A variety of supports were identified with emphasis on carers' centres and voluntary organisations. These included emergency card schemes, future planning toolkits and contingency planning systems.
- d) While only 2 of the 16 questionnaire respondents indicated that a policy on emergency planning existed in their area, the majority stated that emergency planning should have a high priority.

Research Phase 1: Methodology

Think Piece Event Picking up the Pieces Workshop

Following the preliminary research phase, a workshop was held in July 2011 to establish a baseline indicator of practice across the country.

The purpose of this event was to:

- Discuss how carers are currently being supported to make plans for emergencies;
- Share information on good practice;
- Consider how emergency planning can be further embedded particularly within Carer's Assessments.

Over 100 people including family carers and staff from local authorities, health boards and voluntary agencies attended. Key themes were established from the perspectives of both service users and service providers.

Emergency Planning Pathways Event

A further event was held in January 2012 following on from the Picking up the Pieces event in July 2011, to further develop the themes established. The event brought together practitioners and carers with the twin objectives of reviewing existing emergency planning tools and protocols, and considering the development of these and other tools and protocols through the creation of a Best Practice Emergency Planning Pathway.

Telephone Interviews and Full Questionnaires

To complete the information gathering stage of the first phase of the research exercise, a questionnaire containing 19 questions (Appendix 2) was created to obtain information on emergency planning provision from local authority contacts. It was sent by email in November 2011 to all identified contacts in the 32 local authorities. In some cases, it was completed and returned by the local authority contact and in others a phone interview was held with the researcher who populated the questionnaire on behalf of the local authority.

Additional staff support was secured to assist in the information-gathering process. This approach ensured a higher response rate than the preliminary questionnaire.

By the end of December 2011, 28 responses had been received, although not all of the questions were completed in each response. By March 2012 information had been received from 31 local authority areas out of a possible 32. During March and April 2012, the populated questionnaires were returned to the original respondents to be checked for accuracy.

Following the completion of the information-gathering exercise, all completed questionnaires were passed to an independent researcher who undertook basic analysis of the results.

Research Phase 1: Findings

Picking up the Pieces Workshop

Discussion Themes from Carer's Perspective

Emergency Planning

The general consensus was that, while some carers are proactive, most give little or no priority to planning for an emergency.

Carers deal with immediate everyday needs and while they may worry about emergencies, they have no time to sit down and make a plan.

"I have a plan in my head"

For many carers having a "plan in my head" may be enough in the short term, but others have no networks of family or friends who can pick up the pieces in an emergency.

Often wrong assumptions are made about what other family members are able or willing to do in an emergency.

"We have always coped and will do so in the future"

On the other hand, carers tend not to ask for help. They have their own coping strategies which they develop and assume full responsibility for the person they are caring for.

Who normally provides care in an emergency?

There was an overall perception among participants that, for those carers who are able to access alternative care, friends or a relative are the preferred options before social services, as familiarity with the cared-for person is important.

While some carers may rely on neighbours in an emergency, this was considered unsustainable. However, questions were asked about whether friends/family would be available for immediate assistance given that many families are now very dispersed.

Siblings

Carers feel that siblings have their own responsibilities and commitments with their own families and that it is unfair to burden them with extra responsibilities. Many siblings will not be aware of the full responsibilities of the caring role.

These themes are further explored in the report on the focus groups involving siblings.

Unidentified Carers

Many carers are unknown to statutory and/or voluntary services and therefore are not identified as needing help to plan. People don't identify themselves as carers, particularly if they are not connected with services. Nor indeed do carers identify themselves in the role of emergency planner.

Crisis

The impact of a crisis, such as a health scare, often brings the issue to the fore. Only then does emergency planning become a reality. This is often the trigger to put something in place but more often "life takes over again" and carers continue as they have always done, coping on a day-to-day basis.

Longer Term Planning

While the focus of the workshop was on planning for emergencies, the connection to long term planning was an inevitable discussion, particularly for carers who were ageing and continued to care for family members living at home. Planning for the future can be a very difficult proposition for many families and carers. The key barriers to planning included:

- Families don't know where to start; who to go to; where to find information or what to do;
- Future planning is a sensitive issue, challenging family assumptions and requiring people to face their own mortality and discuss personal issues and information;
- Many carers are too busy or tired from day-to-day responsibilities to be able to find the energy to undertake the complex and time-consuming task of planning for the future;
- Many ageing carers may not have expected their son or daughter to outlive them and may have unrealistic expectations around what governments, services and family members can provide when they need to relinquish care.
- Losing continuity of care: it is difficult when care workers move on. No-one knows the cared-for person better than the carer.

“It's daunting to start up”

The impact of not planning, however, can be far reaching, particularly on the wider family. The consensus among workshop participants was that carers needed to be confident that their future plans would be actioned, despite a lack of guarantees about what can be provided in terms of support and resources in the future, particularly given the current financial climate and increasing demand on services.

Picking Up The Pieces Workshop

Discussion Themes from Services' Perspective

What's available to help carers plan for a potential emergency?

Participants felt that there was very little available to specifically help carers plan for an emergency although there were generic sources of support available to carers.

Role of Health

A particular reference was made to the role of health services in supporting carers. In particular, GPs would be able to identify carers and their plans for an emergency as well as providing them with information on support services.

NHS Dumfries and Galloway is developing a carers' register and hospitals seek to identify carers when patients are admitted.

In **NHS Tayside**, in 2010-11 around 430 new carers were identified by workers who link with GP practices and pilot work in secondary care settings.

Emergency Respite Places

Participants agreed that there was diversity across the country in relation to the availability and appropriateness of respite provision. One carer was offered respite for her son outside her local area when she was admitted to hospital. This was unsuitable as the distance and travel costs made it difficult for other relatives to visit him and therefore increased his isolation and anxiety. There was also little opportunity for him to visit his mum in hospital during this period.

Prioritising Carer Groups for Emergency Planning

This was an area of discussion where opinion was divided. Some participants thought that it would be difficult to prioritise any key group of carers as emergencies could happen at any time to anyone.

"If a carer asks for support to have a plan either through the Carer's Assessment or other sources it should be available to them."

Other participants believed that prioritisation is a practical reality when resources are limited.

"On a person-centred basis based on individual needs."

"A common-sense rather than "equality" approach is needed".

It was agreed that some individuals are more likely to have an emergency and taking a proactive approach to planning for these carers could avoid many anxieties and uncertainties. The groups who fall into this category are wide and varied but would include those listed below, in no order of priority:

- Carers with existing health issues or addictions;
- Carers who are on their own;
- Older carers;
- Young carers;
- Mutual carers;
- Terminally ill carers;
- Disabled carers or those in ill health;
- Carers of multiple people;
- Carers admitted to hospital;
- Hidden or unidentified carers.

Who carries out an Emergency Plan?

The consensus was that construction of the emergency plan did not necessarily need to be carried out by a social worker and that there was a role for the Third Sector in providing information and supporting carer groups to plan. Using Carer Information Strategy funding was suggested as a route to fund some of this work. If the issue was actively being raised with carers, it is likely that many more would want to make plans for themselves without the involvement of statutory services.

Planning Services

Participants were in agreement that including carers in the planning and delivery of services is vital.

“Listen to the family member.”

“Treat carers as full partners.”

Early Intervention/Planning

There was a clear view that services should be designed to take a preventative rather than a reactive approach to best support carers.

“Someone needs to ask the question about planning.”

Flexibility and Accessibility

Flexibility, accessibility and less “red tape” were other key concepts identified by participants as being features of the services they would use in an emergency. In particular, the suggestion was made that GPs need to be more flexible, for example offering to talk to the carer privately, as well as the cared-for person if required.

Carer Emergency Identification Schemes

ID or SOS carers’ badge schemes were seen as useful, as were Emergency Card schemes but at present the consensus was that nothing was co-ordinated or universal.

Support Groups

The role of established carers groups such as those facilitated to provide information and peer support, for example the **Princess Royal Trust for Carers (PRTC)** and others can be extremely helpful. There are also many condition-specific support groups. These groups could raise the topics of emergency and future planning.

However not all carers will attend groups or be linked into services and there needs to be consideration of how to reach this group. With the lack of priority given to emergency planning, this is a particular challenge.

Existing Community Alarm Schemes

These are set up to provide 24-hour emergency cover enabling those who are considered to be medically at risk to raise the alarm and call for immediate assistance from specified contacts. There could be merit in exploring the further development of these schemes in relation to carers’ needs.

Good Practice

Integrated Approach

Renfrewshire Council operates a “Message in a Bottle” scheme: they expect the local strategy to recommend the development of this scheme. There is an Emergency and Future Planning for Older Carers Project run by Renfrewshire Carers’ Centre and funded by the Big Lottery. This service integrates a carer’s emergency card scheme with an emergency plan and will alert services that a plan is in place in the event of an emergency.

Health Passport

Inverclyde Council has a Health Passport for carers. In addition GPs automatically give double appointments to carers of children with learning disabilities.

Plans and Life Books

Life Books detail the family's health, routines, social and family networks and professional agencies involved in the cared-for person's life, including details of what should happen in the first 24 hours of an emergency. The **Edinburgh Development Group** provides this service for older carers of people with learning disabilities. Lodging the plan within Social Work Services brings additional peace of mind.

ENABLE Scotland is delivering a Big Lottery funded project to develop emergency planning support services in Dumfries and Galloway and Ayrshire. These services have been supporting older family carers of people with learning disabilities to have emergency plans and to develop personal profiles of the family members they support. Over the three year duration of the project, substantial progress has been made, resulting in carers' emergency plans being channelled through emergency social work provision.

Identification of Carers

Moray Council has established a partnership group called the Carers Service Provider Network, which brings together respite and specialist mental health teams. A joint register of all known carers is under development for the first time. This will make communicating with carers easier and more efficient.

Designated Social Worker Model

Between 2006 and 2011, **South Lanarkshire Council** employed a social worker in a dedicated role to support carers of adults with a learning disability. As part of the objective to develop evidence-informed practice, a team of social workers including the dedicated worker visited 166 older carers across South Lanarkshire to discuss emergency planning, among other issues.

The Council reported that it is using the feedback gained directly from the visits to shape practice by researching housing models, quantifying housing need, piloting emergency planning, and building future planning into the support planning process for older carers.

Emergency Respite

ENABLE Scotland's Glasgow branch has a designated place within their main supported accommodation initiative. Carers who want to make use of the facility, should an emergency arise, are encouraged to build relationships with the staff team who can get to know the needs of the individual. This brings peace of mind. Linking with the staff team has meant that some people who have been supported on an emergency basis go on to attain full time permanent accommodation within the facility.

Community Alarm

In **Angus** carers are provided with a card, which has a unique reference number. In the event of an emergency, Community Alarm staff contact the designated emergency key holder. They can also make arrangements any time of the day or night for alternative care to be provided by Social Work staff until a more permanent solution is found.

Examples of Carers Card Schemes

There are a number of card schemes in place to support carers in the event of an emergency.

Carers of West Lothian in partnership with **West Lothian Council** and stakeholders introduced a card scheme in 2003. The card is given to all carers who come into contact with the Carers Of West Lothian Project. Social Work has considered putting these cards onto the Social Work Information Team system; this has not yet been implemented.

Within Midlothian and Edinburgh **VOCAL** provides an emergency card scheme. The card is completed by the carer and held by the carer and the cared-for person. The card gives the name and contact details of whom to contact in an emergency along with details of the condition and needs of the cared-for person. The cards are not linked to the local authority.

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Emergency Planning Pathways Workshop

“Every person who is entitled to request an assessment of their ability to care, and who wants an assessment, should have a comprehensive assessment carried out quickly after requesting the assessment. The assessment should be reviewed systematically to take account of changing circumstances affecting the carer, cared-for person and other relevant people. The assessment should cover the need for emergency planning so carers have a plan to cover emergency situations.”

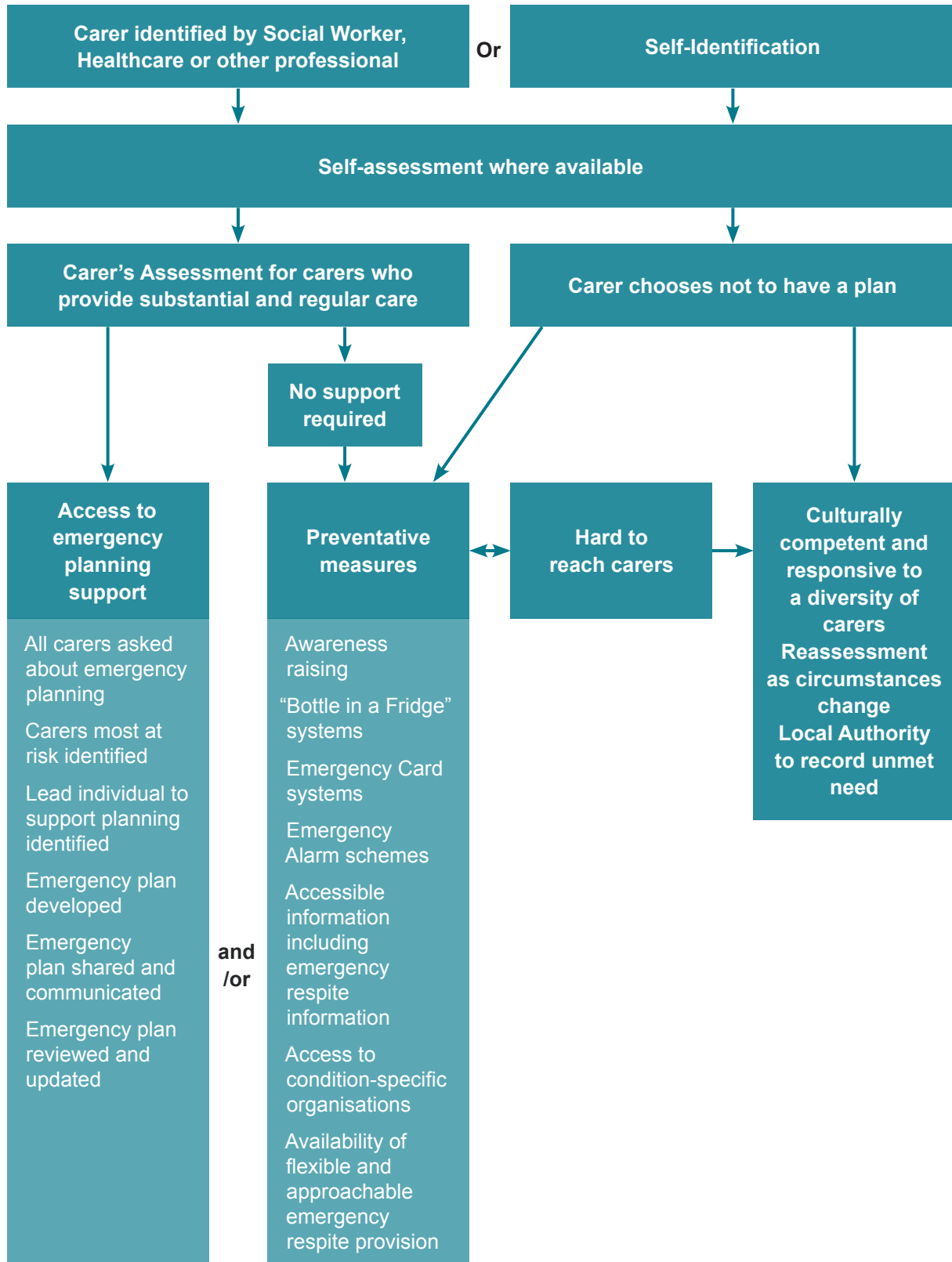
Extract. ***Caring Together*** and ***Getting It Right For Young Carers, the Carers and Young Carers Strategy for Scotland 2010-2015***

Emergency Planning Pathway

The participants worked on developing a Carer Pathway for emergency planning within the context of Carer's Assessments (see Figure 1 on the following page).

The Pathway builds on the framework Carer Pathway outlined in *Caring Together*. It can be found in Appendix 5 of this report.

Figure 1: Recommended Emergency Planning Pathway



Key Points Related to Recommended Pathway

Carer identified by Social Worker, Healthcare or other Professional

NHS and social care professions are considered as the best route to identify carers, through their contact with carers and their families. Health or social care practitioners should proactively engage carers to consider the need for emergency or contingency planning.

Self-Assessment where available

Self-assessment was seen as a gateway to screening which would likely trigger a full Carer's Assessment for those who needed it. Detailed questions on emergency planning are less likely to be relevant at this screening stage.

Carer's Assessment for carers who provide substantial and regular care

In line with the National Minimum Information Standards, all Carer's Assessments should hold details on whether there are measures in place for emergency or crisis planning. This should involve outlining the carer's measures should an emergency arise. If the carer does not have measures in place, there should be a discussion on what would need to be done should an emergency arise.

Carers most at risk identified

While all carers should have a plan for an emergency there will be individual carers whose personal situation may merit further exploration. These carers, such as frail elderly carers, should have the opportunity to access emergency planning support to prevent future crises.

Emergency Plan Developed

A good emergency plan contains:

- Detailed information on the cared-for person and his/her daily and weekly routine with as much input from the cared-for person as possible;
- Details of the people and organisations that would provide care;
- Details of any legal arrangements in place, e.g. Guardianship Orders, Power of Attorney;
- Details of the cared-for person's personality and personal history;
- Medical and personal care information;
- Details of friends and family and the important people in the life of the cared-for person;
- Likes and dislikes;
- Strategies for dealing with specific situations e.g. challenging behaviour;
- Emergency contact information;
- Details of where the cared-for person would stay – would he/she move out or have carers coming in?
- Details of a named person or people who the cared-for person trusts;
- Identification of who's responsible for what;
- Details on who has overall control in the emergency (this might not necessarily be one person).
- Evidence of consent and an agreed review date.

Emergency Plan Shared and Communicated

All emergency planning information should be shared electronically with the appropriate professionals and agencies.

A lead individual should be identified, particularly where an emergency response was imminent.

Plans should be accessible to the emergency services, social work and health (particularly out-of-hours services).

Emergency Plan Reviewed and Updated

As part of a regular process, the emergency plan should not only be reviewed on a regular basis but any changes should be fully recorded and communicated to all relevant individuals and agencies.

Preventative Measures

Awareness Raising

There are key groups of professionals who are well placed to recognise caring responsibilities and have the skills to appropriately engage with carers. For example on admission and discharge from hospital (in relation to either the carer or cared-for person) consideration should be given to how the family may cope when the patient goes home. Asking the question about what the carer and cared-for person would want to happen should an emergency arise in the future needs to be addressed.

- Services such as Patient Information Centres (which are 'one-stop-shops' to quality assured patient information) should provide information on what would be available locally should an emergency arise. This would be beneficial to carers and their families using these centres.
- GPs should also have opportunities to discuss wider carer issues during routine or annual health checks as many of the major health concerns of carers often relate to stress and anxiety.
- Workforces in different communities need to be 'carer aware' as not all carers are linked into social work or health services. Many condition-specific organisations are well placed to introduce emergency planning to carers through carer training and through the distribution of many of the tools available such as carer emergency cards and the "bottle in the fridge" approach.

Hard to Reach Carers

There are communities of hard to reach carers that are less likely to be visible and the development of robust emergency planning systems must take into account cultural differences and the uniqueness of individual caring situations.

Telephone Interviews and Full Questionnaires

The telephone interviews and questionnaires confirmed the snapshot information obtained from the returns in the original preliminary electronic survey.

Local Carers Strategy

“Do you have a local Carers Strategy?”

Total Responses	31	
Yes	29	94%
No	2	6%

Summary

The vast majority of local authority areas reported the existence of a local Carers Strategy. Many are in the process of updating existing strategies in line with national guidelines.

Sample Responses

Aberdeen City Council highlights that although no local document exists, support for carers is a top priority for the council and the Community Health Partnership. A recent survey of carers and their needs has been completed.

Aberdeenshire Council's Carers Strategy expired in 2009 and has been replaced by strategic outcome statements which identify priorities and actions. The Carers Strategic Outcomes group has responsibility for identification of the priorities and development of the action plan relating to carers.

Dumfries & Galloway Council has an existing strategy with a new strategy for 2012-2017 in its final stages. Health staff, social work staff and carers have co-produced the draft, following in depth consultation, including holding two carers' consultation events.

Local Carers Strategy and Emergency Planning

“Does the present strategy contain any reference to emergency planning?”

Total Responses	29	
Yes	10	34%
No	12	41%
No, but under discussion	2	7%
Not applicable	5	17%

“Is it likely that there will be any direct reference to emergency planning in any future strategy?”

Total Responses	27	
Yes	19	70%
Don't know	3	11%
Under discussion	5	19%

Summary

At present there is a mixed picture across Scotland in terms of local Carers Strategies referring to emergency planning for carers. However, responses indicate that many local authority areas will build in direct reference to emergency planning for carers in future Carers Strategies.

Sample Responses

In **South Lanarkshire** an emergency planning protocol has been developed and is to be piloted. The respondent suggested that the anticipatory care agenda under “Reshaping Care for Older People” could link to emergency planning.

In **East Lothian** and **Inverclyde** a worker has been recruited through the Change Fund to complete emergency plans for carers.

Dundee City Council considers that a personal approach to emergency planning is the key, as some carers just need support in the first 24 hours, while others need more intensive planning.

Carer's Assessments

"Who is responsible for undertaking Carer's Assessments in your area?"

Total Responses	29	
Social Worker only	11	38%
Social Worker with carers' centre/other professionals	16	55%
Third Sector only	2	7%

Summary

In almost all cases a social worker is responsible for carrying out a Carer's Assessment. In the majority of cases there is also input from other professionals such as occupational therapists, community nurses, community care assistants and other agencies, including carers' centre staff.

Sample Responses

North Ayrshire Council was among many reporting a low uptake of Carer's Assessments.

Dumfries & Galloway is exploring new methods of increasing uptake for new carers while **North Lanarkshire** planned to identify carer issues and fast track carers to the appropriate support.

In **Glasgow**, nursing staff employed through the Carers Information Strategy also complete screening assessments as part of holistic health checks.

Carer's Assessments and Self-Assessment

"Do you have a self-assessment protocol for carers?"

Total Responses	28	
Yes	16	57%
No	6	21%
Under development/being piloted	6	21%

Summary

The majority of respondents indicated that a self-assessment protocol for carers existed or was under development. In many cases, carers are offered help to complete the self-assessment process.

Sample Responses

City of Edinburgh Council reported that a full assessment is always carried out following self-assessment.

Clackmannanshire Council reported that the self-assessment tool was being redeveloped due to low levels of use.

Carer's Assessments and Emergency Planning

"Is emergency planning included in the Carer's Assessment?"

Total Responses	28	
Yes	22	79%
No	5	18%
Under development/being piloted	1	4%

Summary

Responses indicated that emergency planning is included as part of the Carer's Assessment in the vast majority of local authority areas.

Sample Responses

West Dunbartonshire Council tracks whether a carer has the capacity to continue to care at the review stage.

Moray Council reported that a good deal of work is being done in this area, establishing whether a carer has a plan, if so, who knows about it, and if not, starting to develop one.

In **Renfrewshire**, social workers are encouraged to put people in touch with the carers' centre for help with emergency planning, via the Emergency and Future Planning for Older People's Project.

Emergency Planning in Practice

"If a carer does not have a plan for an emergency, what action do you take?"

Total Responses	29	
Note the situation only	2	7%
Support carers to develop a plan	15	52%
Support carers at risk to develop a plan	5	17%
Other	7	24%

"If you support carers to develop an emergency plan, who is involved?"

Total Responses	25	
Carers only	2	<1%
Carers and cared-for person	3	1%
As above with wider family and networks	12	48%
At social worker's discretion	1	0.5%
Don't know/other	7	28

Summary

The majority of respondents indicated that carers are offered support with emergency planning. The greatest proportion of local authority areas include the carer's wider family and networks when developing the emergency plan.

Sample Responses

Argyll & Bute Council would work with the relevant healthcare professionals to help ensure the cared-for person will be looked after should the carer be unable to care. The carer's wishes regarding who is involved with the emergency plan process are followed.

Highland Council reported that they deal with the crisis first then look at planning for an emergency.

Scottish Borders Council offers carers who wish a plan the choice of registering for a Bordercare Alarm, and/or the emergency card scheme. An anticipatory care assessment can also be carried out by a district nurse.

West Dunbartonshire Council reported that their approach is to hold a dialogue with everyone concerned and look at informal support first.

Destination of Emergency Plans

"What is the final destination of the emergency plan, i.e. who holds the information?"

Total Responses	25	
Social Work only	9	36%
Social Work and carer	8	32%
Social Work and carer centre	1	4%
Carer only	1	4%
Carer's choice	2	8%
Not recorded/don't know	4	16%

Summary

Respondents reported that the majority of emergency plans are held by Social Work services, either exclusively or alongside the carer. Many respondents also stated that all emergency plans are accessible to out-of-hours Social Work services, although no local authority area routinely provides emergency services (police, fire, health) with access to emergency plans.

Sample Responses

Highland Council has an integrated health and social care database.

South Lanarkshire Council operates a Lifeline Service for older carers which is linked to the emergency services.

Stirling Council reports that it does not have a joint electronic database with health, but that a copy of the plan should be held in medical notes.

Supporting Carers to Plan for an Emergency

“What services are available in your area to support carers to plan for an emergency?”

Responses indicated that outside local authority Social Work services, carers’ centres, carer partnerships and other health professionals provide most of the support available to carers to plan for an emergency. Support offered includes short break projects, befriending and learning and development opportunities for carers. A full list of the main types of organisations available to provide support is included in Appendix 3.

In addition, eighteen local authority areas (78% of those who responded) were aware of support services available to siblings or secondary carers provided through a combination of statutory and voluntary services.

Sample Responses

Inverclyde and Stirling Councils have created a specific post to work with young carers.

In **Clackmannanshire**, support to siblings is provided through children’s and mental health services. “Health Spot” is a multi agency initiative which visits schools in the area. Young people can drop in to this. It was recognised that young carers may also be affected by emergency situations which impact on their caring role, such as being delayed at school.

In **Highland** no distinction is made between primary and secondary carers. **Argyll & Bute Council** takes a “holistic approach” in which siblings and secondary carers are provided with equal support to the primary carer.

“What priority should emergency planning have within Carer’s Assessments?”

Total Responses	29	
High	22	76%
Medium	4	14%
Depends on individual cases	3	10%

Summary

With the vast majority of respondents indicating that emergency planning should have high priority as part of the Carer’s Assessment process, this suggests that local authorities recognise the value and need for emergency planning.

Research Phase 2: Methodology

Siblings focus groups and phone interviews

An external facilitator involved a total of 11 sibling carers, conducted one focus group and a series of individual interviews during the autumn of 2011 (Appendix 4). The aim was to explore issues around siblings as providers of emergency care, siblings as carers in their own right, and also as support for parent carers.

A diverse range of siblings was involved, all of whom live in Scotland, primarily in the west, and all with an adult sibling with a learning disability.

The interviewees were men and women aged between 30 and over 60. Some lived with the sibling in receipt of care, others lived nearby, and one interviewee cared for a brother based overseas. Most of them were in employment, and some had children. The ethnic origin of the interviewees was consistent with the Scottish population profile as a whole, mostly White Scottish with one interviewee from a Black and Minority Ethnic background.

It is important to note that the sample was limited by its very nature, as the interviewees and their families were identified by ENABLE Scotland. The sample is representative of families with access to support and information. Had participants been identified through a carers' centre or by GP records, it is anticipated that the responses would have indicated a lower degree of "self-reliance".

Research Phase 2: Findings

Siblings focus groups and phone interviews

Emergency Planning

“What would happen if an emergency arose in your family, and the current caring arrangements were affected?”

As might be expected, there was significant diversity amongst the interviewees' responses to the topic of emergency planning. Some were well-informed, with clear, written plans; some were able to offer a strong safety net for their sibling, while others represented the opposite end of the spectrum.

While most felt able to cope with disruption to current care arrangements in the short term, the majority would be dependent on support from social services if the emergency were longer term.

“Depends on the nature of the emergency. I have two sisters, one stays along the road, she would step in if Mum and I needed extra help. If it was short term, we would cope between us, long term we would get additional help from external sources.”

“I am the support – the worry is what would happen if something happened to me, or my mother really needed me with her – my brother would have to come too. There is no emergency support – only social work services.”

“Does your family have a plan for what should happen in an emergency – e.g. practical details, knowledge of the needs of the cared-for person and their routines?”

The majority of interviewees' families have no written plan for emergencies – though some feel they have enough information available to cope.

Most of those interviewed commented that, as a result of being questioned about an emergency plan, they recognised the need to put one in place. This was particularly true for those with other siblings, and less easy to consider for younger siblings (younger in age, not birth order), who were aware of the sensitivity required when considering a future in which their parents are no longer able to care for their sibling; or indeed to challenge an assumption that they would simply step into the vacant full-time caring role.

Those who did have a written, detailed plan in place tended to be those who were in some way connected closely with **ENABLE Scotland**, or who worked for social services. None of the interviewees reported having been encouraged by social work or other services to put a plan into place.

“No plan – my son knows his routine, because he lives here too and can stay with him...but my son has to go to work every day, and other things...it isn't fair to ask him to take on the responsibility.”

“No written plan – we had a recent experience which showed us that, while we all hold a good deal of information about my sister's routines and needs, there is a great deal only in my Mum's head. It probably would be a good idea to work with her to get it all written down.”

“What support or information is available to you with regard to planning for an emergency?”

When asked about the type of support that is available for them in relation to planning for an emergency, the interviewees' responses highlighted the differences between carers who are personally connected to service providers and those who are not.

*“I sit on **ENABLE Scotland's** committee; part of the reason for this was to make sure the family become networked and get access to information about help that (sibling) could get. I also have friends who are social workers who are very helpful.”*

“We have a social worker and key worker at the day centre. We rely heavily on them. I don't know with the changes to funding whether this is going to impact on what they can offer in the future”.

“What information or help will support your role as a sibling carer, in your personal situation?”

The interviewees were asked about the type of information or support they would like for planning to cover emergencies. Even amongst this well-resourced group, there were reports of poor support from social services in relation to information and assistance with making arrangements. Given recent moves in Glasgow to self-directed support and individual budgets for adults with learning disabilities and council spending cuts, many interviewees reported concerns for the future.

“What I would like is respect and recognition for what I do for (sibling) and information about resources without having to go looking for it myself”.

“Information about services and resources that sibling could get access to. When you get in touch with them they tell you “we don't run that service any more or we don't have the resources to do that any longer”.

“What information or help will support your family to cope in an emergency?”

The interviewees were also asked about what would support their family in the event of an emergency, i.e. what would they like to be in place?

“There should be emergency beds in every unit in the city. The only way to care for my brother in an emergency is for him to be taken in...and that should only be somewhere familiar to him. Not very likely to be available –so whatever emergency I am dealing with will be made worse by worrying if he is OK.”

“English is my first language, but my mum is the main carer and relies on me for information as there is not a great deal translated into minority languages. That is a need. Also in relation to Single Shared Assessments – information goes out of date...who is responsible for keeping it up to date?”

Role of Sibling Carers

“What support do you provide at the moment to the primary carers, and your sibling(s)?”

The interviewees were questioned on their role as sibling carers, particularly when the primary carer is still the parent. Topics covered included the current support they provided to their sibling, and how they imagined it changing in the future.

The results indicated that geographical proximity shaped the caring role that siblings have. Several participants reported that they attended to personal administration, liaised with support staff and other logistical supports. Two participants also reported taking on the official role of advocate for their siblings.

“I provide full care including personal care, advocacy, dealing with finances and professionals. My sibling attends a day centre, we have personal assistants for part of the weekend and occasional respite as well.”

“I support my sister through providing emotional support to my mum, who is the primary carer...I offer respite care to give my parents a break, and I act as (sibling's) advocate.”

“Does the fact that you have a sibling with a learning disability impact on your own future plans?”

“Do you feel that you will be responsible for the care of your brother or sister if the time comes when your parents are no longer able to provide support?”

The siblings were asked about their visions of the future – how they are impacted by their relationship with their sibling, and whether or not they imagine a time when they will become the primary carer.

“Life becomes conditional on your caring responsibilities. I would like to move, but don't want to unsettle my sibling, she has routines and there is a network of support here for her. Respite helps me a lot.”

“I hope to become a parent myself in the future, and am not sure how I would manage my sister's fulltime care as well. I think the best arrangement for her would be to live independently, with carers coming in and me over-seeing things. However, I know that isn't how my father imagines the future – he is very protective of her.”

Conclusions

Phase 1: Emergency Planning

Having a plan and knowing what will happen should an emergency arise is fundamental to the emotional wellbeing of carers. It makes a key contribution to their confidence in managing and continuing with their caring role. It is a preventative measure and aligns with local and national key outcomes for carers.

Key to Several Policy Agendas

The research undertaken in the production of this report indicates that emergency planning for carers is receiving increased priority in most local authority areas.

Updated carers strategies in many areas now reference emergency planning as a key area for growth and development and this is commended.

Emergency planning dovetails also with other policy agendas such as:

- Reshaping Care For Older People;
- Scotland's National Dementia Strategy;
- Health Care Quality Strategy;
- Mental Health Strategy for Scotland;
- Improving the Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan.

Significant Variation Across Scotland

In addition, the proposals for the integration of Adult Health and Social Care and the Self-Directed Support Bill could have implications for a more effective approach to emergency plans for carers.

Despite this increase in profile, however, current provision of emergency planning support services to carers across Scotland is piecemeal and inconsistent; with the levels of support offered to carers dependent on location rather than need and varying greatly in nature.

A major issue relating to the provision of services to carers, whether emergency planning or otherwise, is the requirement to firstly identify

the carers. Many carers are unknown to carer support services for a variety of reasons.

Some do not view themselves as carers but rather as partners, parents, family members or friends.

Others are unwilling to engage with social services and many lack knowledge of the support that is available.

Those carers who are known to services tend to live on a day-to-day basis and while many have anxieties about emergencies occurring and about the long term future, taking time to formalise a plan is not a common occurrence.

Many carers may have an ad hoc arrangement, which would suffice on a short-term basis but it is recognised that this cannot offer the same benefits in terms of peace of mind as a structured and recorded contingency or emergency plan.

An emergency plan, however, may not necessarily involve contributions from health or social work services. Rather, for most carers, it would be a preventative approach involving family and personal networks in the first instance.

However, there are also groups of very vulnerable isolated carers who have no informal networks to support them in an emergency and these carers are at particular risk and will need identification and proactive interventions by the most appropriate agency.

Future Opportunities to Develop Good Practice

Nationally the low uptake of Carer's Assessments is recognised and there is much work being undertaken at local and national level to increase the quality and uptake of Carer's Assessments.

Within Carer's Assessments across Scotland, there is great variation in the information requested from the carer about his/her plans for an emergency. There is also variation in the action taken should a carer not have a plan for an emergency.

For many carers an emergency situation may be an indicator of a future crisis situation that needs preventative interventions, for example, the deterioration of the carer's health or the escalation of the cared-for person's needs. Situations such as these do not necessarily trigger preventative measures either by the carer or through statutory provision.

Some of the specialist services available to provide carers with the proper support to create emergency plans have developed effective tools and integrated systems of support. Many of these are through short term funding programmes such as the Big Lottery Fund.

However the research indicated that there are resources and agencies, including those in the voluntary sector, which could be available to support emergency planning, given more awareness raising with those agencies who interface with carers.

The research highlights that there is a real interest in sharing and developing good practice, indicated by the attendance at the events organised and the willingness of local authority areas to inform the report by responding to questionnaires and giving time to talk to researchers.

There was acknowledgement, however, that more work needs to be done to share knowledge, integrate good practice and avoid duplication of work.

Phase 2: Siblings

Siblings play a unique role in the care of brothers and sisters with support needs – and being a family carer is a key consideration for most when planning their futures, with many siblings' life experiences being affected both positively and negatively by having a family member with a disability.

Many siblings are initially secondary carers who progress to become primary carers, particularly when a parent carer is unable to continue in the caring role.

In Scotland there is little recognition of the role of siblings in the care of adults with support needs as distinct from the role of the primary carer. There is also a lack of opportunity for siblings to network with and learn from one another.

As secondary carers, many siblings are not involved in the emergency or future planning process. Assumptions may be made by primary carers about the future caring role of siblings, which are not discussed as a family, possibly due to the emotional nature of the subject.

Recommendations

Carer's Assessments

An improved uptake of Carer's Assessments could correspondingly improve the uptake of emergency planning services. There should be a focus on improving the quality of Carer's Assessments to include emergency planning. All local authority areas should ensure that as a basis all Carer's Assessments adhere to the minimum expectations on emergency planning outlined within the National Minimum Information Standards.

Where carers identify the need for an emergency plan within a Carer's Assessment, support should be provided to ensure that the carer has a plan that will work for them. All plans should be reviewed on a regular basis as part of the review process. Best practice would ensure that carer details were held in emergency systems.

Emergency planning must also link to future planning arrangements, particularly for those carers whose situations would put them and/or the cared-for person at risk.

Preventative Measures

Emphasis on early intervention and preventative actions to avoid crisis situations should be the default position within all local authority areas. Carers whose caring responsibilities are minimal should have adequate information to support them should their caring responsibilities become more demanding, possibly with emergency plans in place should their circumstances change quickly.

Empowering carers to effectively manage their own emergency planning arrangements by building confidence in the use of informal supports where possible, is important but will require practical help and support from those local organisations best placed to connect with carers.

Integration/Mainstreaming of Carers Emergency Planning into Policy

This report recommends that emergency planning for carers be integrated not only within *Caring Together's* Monitoring and Implementation Plan but also within all relevant current and future health and social policy.

Appendix 6 outlines the Action Points from *Caring Together* where there is potential to include Emergency Planning. A summary of these actions which are either in progress or will be progressed are:

- The proposed bespoke resource for carers on stress and caring which the Scottish Government and partners will produce;
- Workforce training plans;
- Including emergency planning within staff development materials available through Talking Points;
- The Carers Rights Charter which will set out key principles for carers' support;
- Promoting the role of short breaks and respite as opportunities to reduce the likelihood for crisis or need for emergency provision and developing flexible models of respite provision to reduce the likelihood of inappropriate emergency provision;
- Improving the quality and uptake of Carer's Assessments.

Reshaping Care for Older People

Some local authority areas have realised the potential of the Change Fund to support carers to have future and emergency plans. More local authority areas should look at the potential of this route given that at least 20% of Change Fund resources are set aside to support carers of older people.

Health Boards and Carer Information Strategies

Health boards are using some of the Carer Information Strategy (CIS) funding to provide information and advice to carers. In many cases this is through funding provided to carers' centres and to condition-specific organisations. There are opportunities to include emergency planning support to carers within the context of this funding stream.

Carers Information Zone

Over the past year, with partners, NHS 24 has undertaken a lot of development work on the Carers Information Zone. This is a source of information for carers (and young carers). The inclusion of signposting and other sources of information on emergency planning should be considered.

Carer Identification

Work is underway in a number of local authority areas to strengthen the identification of carers at risk through health professionals such as GPs and hospital discharge teams who are often the first line of contact. There is an opportunity to raise the topic of future crisis planning and prevention given that a health crisis can often be the trigger for carers to review their situation.

Self-Directed Support

The self-directed support approach to social care and personalisation, with systems in place for allocating individual budgets, has the potential to be used to respond to emergencies particularly if preventative planning with families is undertaken beforehand.

Self-Directed Support has the potential to allow carers to have a personalised solution should an emergency arise.

Telecare

Consideration should be given to how telecare systems such as warden schemes could be further developed to provide an emergency response for carers.

Integrated Systems

The use of Carer Emergency Card Schemes or similar approaches should be actively promoted in all local authority areas.

While "stand alone" schemes are an excellent starting point, ensuring an integrated approach with links to local emergency systems is preferable.

Siblings

When parent carers are elderly, services should ensure that siblings are involved in key discussions, receive copies of written correspondence and are kept up to date with impending changes to services and/or funding arrangements.

There could be a real benefit in involving a third party to help families plan for the future, to ensure that all eventualities have been considered; and to facilitate the best outcome for all parties.

'Sibs UK' is a sibling organisation based in England, which recognises the unique role played by siblings, and their presence (or that of a similar organisation) in Scotland would fill an important gap.

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Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015

Edinburgh: Scottish Government

<http://www.scotland.gov.uk/Resource/Doc/319441/0102105.pdf>

Scottish Government (2010)

Reshaping Care for Older People, a Programme for Change 2011-2021

Edinburgh: Scottish Government

<http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/>

<http://www.scotland.gov.uk/Topics/Health/care/reshaping>

Scottish Government (2009)

Improving the Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan

Edinburgh: Scottish Government

<http://www.scotland.gov.uk/Resource/Doc/294270/0090939.pdf>

Change Fund Plans for each of the 32 local authorities:

<http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/change-fund-plans/>

Appendix 1

Preliminary Survey Questions

1. Please provide your name.
2. Please provide your email address.
3. Please provide the name of your local authority/health board area.
4. How is the Carers Strategy being implemented in your area?
5. Who is responsible for undertaking Carer's Assessments in your area?
 - A social worker employed by the local authority.
 - An agency on behalf of the local authority.
6. Do you use a self-assessment protocol for carers?
7. Within the Carer Assessments/Support Plans, what information do you collect from carers on their plans to deal with an emergency?
 - We don't collect information.
 - We identify whether the carer has a plan for an emergency.
8. If the carer doesn't have a plan for an emergency, what action do you take?
 - We note the situation only.
 - We actively support them to develop a plan.
 - We actively support only the carers who may be at risk to develop a plan.
9. If you actively support carers to develop an emergency plan, how do you do this?
10. What services are there in your area to support carers to plan for an emergency?
11. Does your local authority/health board have a policy on emergency planning for carers?
12. What priority do you think emergency planning should have within Carer's Assessments?

Appendix 2

Local Authority Questionnaire: Questions

Local Carers Strategy

- 1 Do you have a local Carers Strategy?
- 2 Does the present strategy contain any reference to emergency planning?
Is it likely that there will be any direct reference to emergency planning in any future strategy?

Carer's Assessments

- 3 Who is responsible for undertaking Carer's Assessments in your area (e.g. a social worker employed by the local authority; an agency employed by the local authority, or other)?
- 4 Do you have a self-assessment protocol for carers?
- 5 Is emergency planning included in the Carer's Assessment?

Emergency Planning in Practice

- 6 If the carer doesn't have a plan for an emergency, what action do you take?
7. If you support carers to develop an emergency plan, who is involved?
8. What is the final destination of the emergency plan, i.e. who holds the information?

Supporting Carers to Plan for an Emergency

9. What services are available in your area to support carers to plan for an emergency?
10. What priority should emergency planning have within Carer's Assessments?

Appendix 3

Local Authority Questionnaire: Sample Responses

Local Carers Strategy

“Do you have a local Carers Strategy?”

Sample Responses

Aberdeen City Council highlights that although no local document exists, support for carers is a top priority for the council and the Community Health Partnership. A recent survey of carers and their needs has been completed.

Aberdeenshire Council's Carers Strategy expired in 2009 and has been replaced by strategic outcome statements which identify priorities and actions. The Carers Strategic Outcomes group has responsibility for identification of the priorities and development of the action plan relating to carers.

Dumfries & Galloway Council has an existing strategy with a new strategy for 2012-2017 in its final stages. Health staff, social work staff and carers have co-produced the draft, following in depth consultation, including holding two carers' consultation events.

In **East Ayrshire**, development of a local strategy is in progress, led by the Carers' Forum, which is part of the East Ayrshire Community Health Partnership.

In **South Ayrshire**, a draft strategy is in progress and will be reviewed at a consultation event in the near future.

“Does the present strategy contain any reference to emergency planning?”

“Is it likely that there will be any direct reference to emergency planning in any future strategy?”

Sample Responses

In **South Lanarkshire** an emergency planning protocol has been developed and is to be piloted. The respondent suggested that the anticipatory care agenda under “Reshaping Care for Older People” could link to emergency planning.

In **East Lothian** and **Inverclyde** a worker has been recruited through the Change Fund to complete emergency plans for carers.

Dundee City Council considers that a personal approach to emergency planning is the key, as some carers just need support in the first 24 hours, while others need more intensive planning.

Moray Council reported that arrangements to create a structure to take forward emergency plans are under development.

Argyll & Bute is currently looking at winter planning where weather can have an impact on carers. **Orkney** also highlights the problems facing island councils where adverse weather conditions can leave carers stranded, stopping them from returning to outlying islands. A **Western Isles** Emergency Planning Coordinating group with a sub group is addressing this theme of wider emergency planning for cared-for people.

Glasgow City Council reported that it was aware of the importance of emergency planning as part of the support provided to carers, and that it was working towards embedding emergency and future planning within its local Carers Strategy.

In a recent survey by **Aberdeen City Council**, responses did not highlight emergency planning as a concern of carers. Concerns were more about how the role of carers is viewed, and respect for the caring role.

Stirling Council states that emergency planning will be carried out in the form of anticipatory care plans.

Fife Council plans to develop a model for contingency planning and emergency cover within Care Plans when a carer is ill or affected by crisis.

North Lanarkshire Council stated that, given the expected growth in the number of older people and a subsequent increase in carers, they would want to see emergency planning in a future strategy. The area has a register of

carers via GP practices, Home from Hospital Discharge Packs, and NHS Lanarkshire Carers Support teams work in three hospitals.

Aberdeen City Council recognised the importance across the health and social care system of reducing emergency admissions to hospital through better support and anticipatory care. Anticipatory Care Plans are now being started via GPs.

Carer's Assessments

"Who is responsible for undertaking Carer's Assessments in your area?"

Sample Responses

North Ayrshire Council was among many reporting a low uptake of Carer's Assessments.

Dumfries & Galloway is exploring new methods of increasing uptake for new carers while **North Lanarkshire** planned to identify carer issues and fast track carers to the appropriate support.

In **Glasgow**, nursing staff employed through the Carers Information Strategy also complete screening assessments as part of holistic health checks.

Shetland Islands Council reported that social workers are responsible for carrying out the assessments but carers are encouraged to use a self-assessment tool.

The Short Breaks Co-ordinator in **Inverclyde** is piloting a new assessment tool. This is to be rolled out through Social Work in **Inverclyde**.

Assessments are usually undertaken by a third sector agency, but carers can request that it is carried out by another professional in **Orkney**.

Aberdeenshire Council has a system where carer support workers can assist with the Carer's Assessment and has also expanded Local Area Co-ordinators (LACs) to support Carer's Assessments. They find LACs bring additional skills and see this as a good model.

Aberdeen City Council reported that very few Carer's Assessments had been carried out and **North Ayrshire Council** reported a similarly low number. **Dumfries & Galloway** is exploring new methods of increasing uptake for new carers while **North Lanarkshire** planned to identify carer issues and fast track carers to the appropriate support.

"Do you have a self-assessment protocol for carers?"

Sample Responses

City of Edinburgh Council reported that a full assessment is always carried out following self-assessment.

Clackmannanshire Council reported that the self-assessment tool was being redeveloped due to low levels of use.

In **South Lanarkshire**, carers can self-refer, be referred by their GP or the voluntary sector.

Glasgow City Council launched a self-assessment pilot in December 2011, informed by Talking Points. The self-assessment is contained within their Carers' Information Booklet.

Aberdeen City Council's existing self-assessment is being overhauled to become more detached from the statutory assessment procedure.

Of those Councils with no self-assessment protocol, **Highland, Moray, Dumfries & Galloway** and **East Dunbartonshire** report that this is to be introduced or is currently being piloted.

Dundee City Council is testing a new format, giving the option of self-completion, but report it likely that it will be recommended the assessment part is completed with support. **Orkney** does not have self-assessment but recognise assessment is "co-production" agreed by the carer.

In **Falkirk**, the self-assessment tool was developed with the carers' centre, with the needs of the carer incorporated into the client information system.

Twenty-three councils reported that there was direct information on emergency planning in the Carer's Assessment. **Aberdeen City Council** highlighted that it takes the form of the national minimum standards.

West Dunbartonshire Council tracks whether a carer has the capacity to continue to care at the review stage. **Moray Council** is doing "much work" in this area, establishing whether a carer has a plan, if so, who knows about it, and if not, starting to develop one. **Argyll & Bute Council**, through the Change Fund, is looking at the need to better embed anticipatory/ emergency planning into the assessment.

In **Renfrewshire**, social workers are encouraged to put people in touch with the carers' centre for help with emergency planning, via the Emergency and Future Planning for Older People Project.

"Is emergency planning included in the Carer's Assessment?"

Sample Responses

West Dunbartonshire Council tracks whether a carer has the capacity to continue to care at the review stage.

Moray Council reported that a good deal of work is being done in this area, establishing whether a carer has a plan, if so, who knows about it, and if not, starting to develop one.

In **Renfrewshire**, social workers are encouraged to put people in touch with the carers' centre for help with emergency planning, via the Emergency and Future Planning for Older People's Project.

Emergency Planning in Practice

If a carer does not have a plan for an emergency, what action do you take?

Sample Responses

Argyll & Bute Council explained that the council would work with the relevant health care professionals to help ensure the cared-for person will be looked after should the carer be unable to care.

Highland Council reported that they deal with the crisis first then look at emergency planning.

Aberdeen City's response was option B or C and they pointed out that a lot of energy is going into this.

Scottish Borders Council asks carers if they have a plan, if not and they want one they have three options and may choose one or all three as listed below:

1. Register for a Bordercare Alarm,
2. Register with the carers' emergency card scheme,
3. Have an anticipatory care assessment carried out by a district nurse.

The areas that did not choose one of the options gave the following information:

Moray Council reported that arrangements to create a structure to take forward emergency plans are under development.

North Lanarkshire Council does not have a separate plan for an emergency.

Dumfries & Galloway Council holds the view that it depends on the professional judgement of the social worker.

Orkney Islands Council explained it supports carers to make a plan where there is a risk that it may be required; otherwise there is no automatic discussion of emergency planning.

City of Edinburgh Council said it depends on individual situations.

Falkirk Council said it depends on a number of factors including the carer's circumstances with further work necessary to ensure a consistent approach.

Glasgow City Council encourages carers to develop an emergency plan in cases where assessment indicates that the person being cared-for could not cope on their own without support.

If you support carers to develop an emergency plan, who is involved?

Sample Responses

Individual case dependent

– **South Lanarkshire Council.**

Dependent on wishes of carer

– **Argyll & Bute, Dundee Councils.**

A dialogue with everyone concerned and look at informal support first

– **West Dunbartonshire Council.**

There are plans for a future toolkit, awaiting funding

– **East Dunbartonshire Council.**

Emergency plans will also be drawn up where there are cases of anticipated need – **Clackmannanshire Council.**

As part of assessment and case management processes

– **Perth & Kinross Council.**

The lead person involved with the carer will encourage the carer to consider what they would do in an emergency

– **Midlothian Council.**

The cared-for person also gets an emergency card and is involved in assessment.

– **Scottish Borders Council.**

What is the final destination of the emergency plan, i.e. who holds the information?

Sample Responses

Highland Council has an integrated health and social care database.

South Lanarkshire Council operates a Lifeline Service for older carers which is linked to the emergency services.

Stirling Council reports that it does not have a joint electronic database with health, but that a copy of the plan should be held in medical notes.

Glasgow City Council gives a paper copy to the carer, to allow NHS staff access to the information.

In **Orkney** if the plan is part of the assessment it will be on file with social work.

Aberdeenshire Council looks for triggers for change when they review the plan.

In **Renfrewshire** a flag on the council's SWIFT system notes that an emergency plan is in place.

South Lanarkshire Council points out that it is important that the emergency plan sits with the council as part of the emergency statutory duty. While the voluntary sector has a role, the legal responsibility should sit with the council.

No council areas routinely provide emergency services (i.e. police, fire, health) with a copy of or access to the emergency plan, however **South Lanarkshire Council** does have its Lifeline Service linked to the emergency services.

Highland, Inverclyde, Stirling, Glasgow, Aberdeenshire, West Lothian and Renfrewshire Councils all mention that the plans can be accessed by their out-of-hours social work service.

West Dunbartonshire Council mentioned its warden support system.

Argyll & Bute Council highlights a more general link with the emergency services with regular meetings where the emergency services can highlight gaps in provision.

In **Renfrewshire** the Emergency and Future Planning for Older Carers Project has ongoing meetings with emergency services.

Aberdeen City Council is working to improve links with the Scottish Ambulance Service.

In the **Western Isles**, GPs would contact Crossroads who have identified workers willing to step in at short notice in an emergency.

Supporting Carers to Plan for an Emergency

What services are available in your area to support carers to plan for an emergency?

Summary

Community Care Forum

Carers Groups/Centres

Specialist emergency planning services

Princess Royal Trust Carers' centre (PRTC)

Emergency duty team

Young Carers networks

Respite Resources

"Message in a Bottle" systems

Care managers

Carers emergency card schemes

Local area coordinators

Community nurses

Carer support teams

GPs, nurses

Care at Home Services

Voluntary organisations

Voluntary carer organisations

Emergency respite beds

Care homes

Telecare

Sample Responses

Inverclyde and **Stirling Councils** have created a specific post to work with young carers.

In **Clackmannanshire**, support to siblings is provided through children's and mental health services. "Health Spot" is a multi agency initiative which visits schools in the area. Young people can drop in to this. It was recognised that young carers may also be affected by emergency situations which impact on their caring role, such as being delayed at school.

In **Highland** no distinction is made between primary and secondary carers. **Argyll & Bute Council** takes a "holistic approach" in which siblings and secondary carers are provided with equal support to the primary carer.

What priority should emergency planning have within Carer's Assessments?

With the vast majority of respondents indicating that emergency planning should have high priority as part of the Carer's Assessment process, this suggests that local authorities recognise the value and need for emergency planning.

Appendix 4

Siblings Interviews and Focus Group: Questions

Schedule of Questions

- What support do you provide at the moment to the primary carers, and your sibling(s)?
- What would happen if an emergency arose in your family, and the current caring arrangements were affected?
- Do you discuss, as a family, what might happen in an emergency?
- Does your family have a plan for what should happen in an emergency – e.g. practical details, knowledge of the needs of the cared-for person and their routines?
- Would you say there is a written plan, unwritten expectations, a vague idea or no actual plan at all?
- What support or information is available to you with regard to planning for an emergency?
- How long could you continue to support your sibling in an emergency situation – i.e. if the emergency became longer term, what would you do?
- Does the fact that you have a sibling with a learning disability impact on your own future plans?
- How concerned are you about the future, e.g. managing multiple responsibilities and/or the long term care of a sibling?
- How responsible do you feel for the time when parents will no longer be able to provide support OR Do you feel that you will be responsible for the care of your brother or sister when the time comes when your parents are no longer able to provide support?
- What information or help will support your role as a sibling carer, in your personal situation?

Appendix 5

Siblings Interviews and Focus Group: Sample Responses

Emergency Planning

“What would happen if an emergency arose in your family, and the current caring arrangements were affected?”

“Never had an emergency, I would be dependent on social services. I have no family here, my brother has moved away. It would fall on me and my partner to step in on the first instance.”

“We are a big family and very close, we have good friends. I am sure any one of them would step in. It would just take a phone call. Sibling can also stay overnight with our mother who is in sheltered accommodation.”

“When I went into hospital two years ago for a knee replacement it took a lot of effort to get a respite bed available where my brother usually goes, at the same time as the surgeon was available. My operation was cancelled twice due to difficulty getting things into place. God forbid we ever had a crisis – there is nothing to put into place without time to organise. There is no family apart from me and my 86 year old mother, who is unwell.”

“My two brothers and I all live nearby, and do step in when needed. We have offered overnight care, and I know her level of personal care needs – as does my sister-in-law. Our family are very close.”

“...a day or two, we have teenagers at home, social work would have to put support in after that.”

“We do plan that he will eventually live with us – so I guess an extended emergency would mean that he lives with us.”

“Depends on the emergency, we would pull together and cope in the short term. We would bring in the right people if we couldn’t cope longer term”

“I dare say we would muddle through...but it would be difficult to do so on our own, long-term.”

“Does your family have a plan for what should happen in an emergency – e.g. practical details, knowledge of the needs of the cared-for person and their routines?”

“I have assumed that social work have a file with all these details, as (sibling) has a care package, but I haven’t checked this with them. My partner would know the basics and could pass these on to the relevant persons.”

“I have a folder for (sibling) with all the necessary details in it, if anything happened. (Sibling) knows where the folder is kept as do the rest of the family.”

“Social work have a written plan and we have a copy of this. I have gathered all the key numbers and written these down.”

“No plan – not even for what would happen if we were on holiday. It is something we need to think about though.”

“What support or information is available to you with regard to planning for an emergency?”

“Because of my work, I have lots of information. Also, because of the type of family we are, we all know someone will step in if needed.”

“We rely on social work and the process we went through with them when writing his personal plan”

“None of us – maybe my mother-in-law has been spoken to, but I haven’t heard about it. He has no social worker at the minute. When I did need something for him it took 6 weeks for someone to be in touch as he had to be allocated to a social worker.”

“What information or help will support your role as a sibling carer, in your personal situation?”

“Nothing needed now. When (sibling) first came to us it was very hard to get the right information, social work weren’t supportive at all”.

“More respite – no thought required... that is what I need. My respite was cut in half without any assessment – in the southwest there is a budget deficit, and the decision to cut our respite in HALF was taken by someone sitting at a desk... Nothing to do with what my brother and I need.”

“Planning information would be useful – maybe we are going along blindly. Some guidance on what should be included in a plan would be helpful. I stay pretty well informed.”

“Mum is becoming forgetful, letters arrive or information is given to her because she has been appointed as the guardian but she forgets to pass it on. It is a lot to expect of her. She may be in the early stages of dementia. We were told by day centre they would copy us into all information but this doesn’t happen. It’s very frustrating!”

“What information or help will support your family to cope in an emergency?”

“I know people in social work and can go to them first. I am sure they would help out or tell me who to speak to.”

“To have a conversation with someone so that I understand what would happen and what to expect.”

*“Because I am involved with **ENABLE Scotland**, I feel confident that I would know who to speak to in such a situation”*

“That is why we are working on the Welfare Guardianship right now, which is nearly completed. There are three siblings, and we all feel an obligation to ensure my sister’s welfare and quality of life.”

“I would just call social work”.

Role of Sibling Carers

“What support do you provide at the moment to the primary carers, and your sibling(s)?”

“My brother can’t read or write; I help him with this. Mum is primary carer, I work full time but I step in if Mum has to go out particularly in the evenings. (Sibling) can be left on his own for short periods. We are a close family and support each other as needed.”

“Full care, supporting daily living. My brother attends a day centre and we have had decent respite – but this has been reduced by 50%.”

“I live across the street – my main role, because I work in the field, is to advise my mum who is the main carer. Particularly in relation to ILF, and to help plan for my sister’s future needs.”

“We do a lot of the practical tasks such as transportation to appointments, making sure there is hot meal for the evening, buying clothes for sibling, dealing with finances and liaising with social work.”

“Everything ‘official’ – his appointments, liaising with day centre...everything apart from personal care.”

“Does the fact that you have a sibling with a learning disability impact on your own future plans?”

“Do you feel that you will be responsible for the care of your brother or sister if the time comes when your parents are no longer able to provide support?”

“He is my brother, so I don’t think of it as hard work – but it is VERY limiting. It reduces all sorts of possibilities for me.”

“Because my parents are very well, I don’t think too much about it. My husband is supportive, as our faith supports our sense of responsibility for our families. However, there may come a time when we need to leave (x) – and while my sister will always be a consideration, it wouldn’t be fair to ask her to leave the place she has grown up, and her own friends...I think we just take one day at a time, but she is always a consideration.”

“I would like (sibling) to go into supported accommodation, but feel guilty about this. I would worry for her. You get used to having the responsibility and I would miss her not being here.”

“I have concerns about finances because there are changes taking place regarding benefits and personalisation of care.”

“I am not too concerned at the moment, but I think that is partly because I have so much information, due to my professional life. If you were to speak with my brothers, they might tell a different story. I know the system, and am confident within it.”

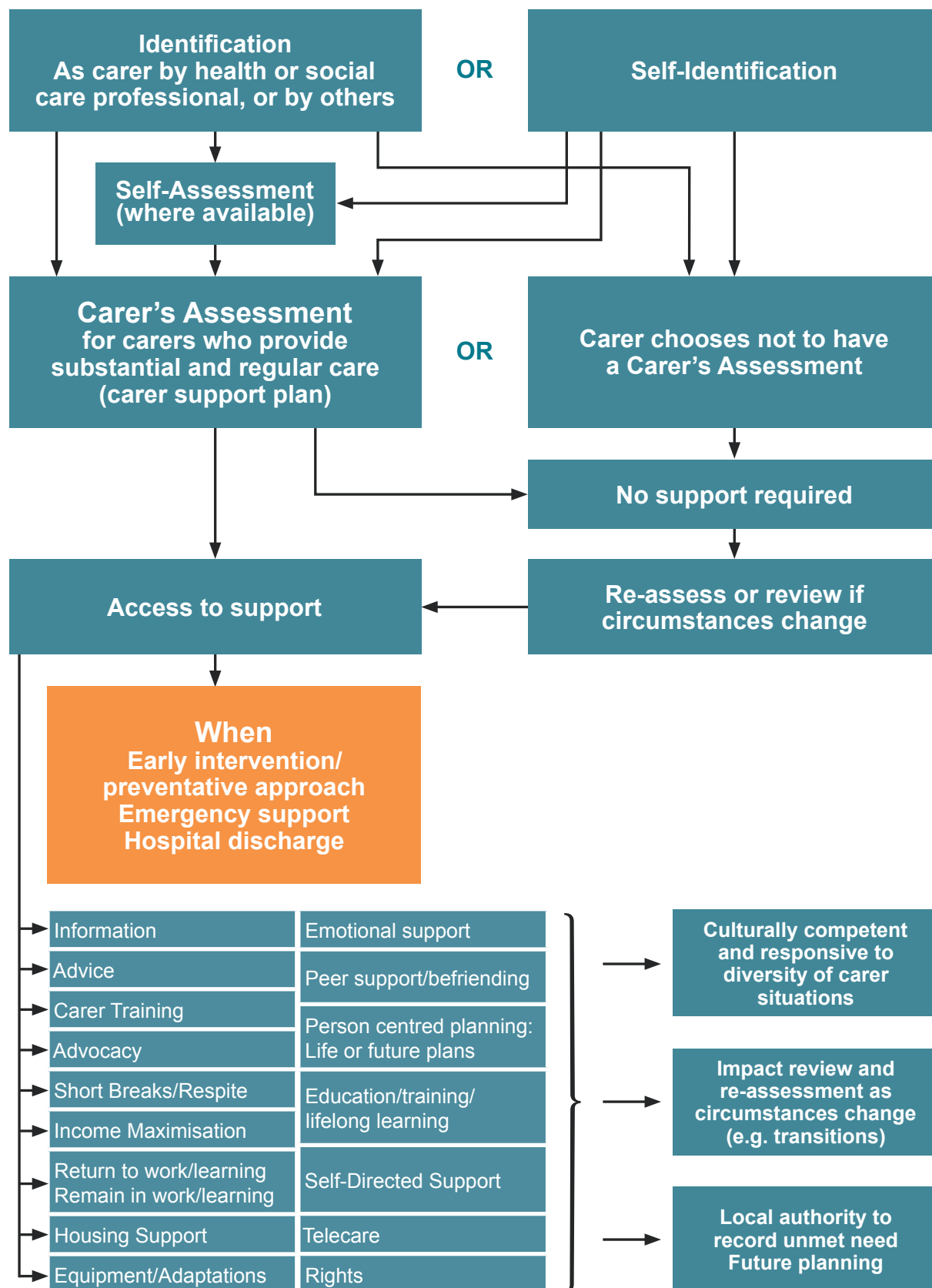
"We are having an extension built onto our house so he has somewhere to live....It is just what we will do – there is no point in getting stressed about it now. Hopefully he will continue to get day care, as my husband and I both work."

"I am completely responsible for (sibling). We knew it was going to happen but it happened sooner than planned due to mum's illness. She (sibling) will always be with us now"

"I don't know how it will work out. It could become more demanding of our time. We have teenagers at home, (sibling) has own routines etc.... it wouldn't work for us all to be together, even though I feel guilty when I say this."

Appendix 6

Carer Pathway Diagram



Appendix 7

Action Points from Caring Together linking with Emergency Planning

Action Points & Implementation Plan		Comments
2.5	By 2015, the Scottish Government will ensure that the intentions to accelerate the pace of sharing good practice under Reshaping Care take account of good practice in supporting carers.	Consider Emergency Planning strategies e.g. designated carer workers supporting carer planning.
3.3	In 2011-12, the Scottish Government will draw up a specification and seek to commission research on communities of carers we know little about including refugees, asylum seekers, gypsy travellers and carers with disabilities, including learning disabilities. (Relevant to young carers too).	Consider sibling carers
4.1	By 2012, if they have not already done so, local authorities with partners, will wish to revisit their local carer strategies to identify and support carers in need according to their own assessment of need. To support this process, the Scottish Government will produce a short list of key points that local carer strategies should address.	All new strategies should action Emergency Planning
4.2	By 2013, local authorities, with partners, will aim to identify carers in greatest need according to an objective assessment of need, and in line with published indicators, which also takes account of the nature and level of risk. They will aim to provide support, or signpost on to support	Consideration of preventative measures in relation to carers at risk of an emergency and carers requiring support for future planning
4.3	Over the next five years, local authorities and Health Boards, with partners, should seek to provide preventative support to carers and minimise the need for crisis intervention.	
4.4	Over the next 5 years the Reshaping Older People's Care Programme will look to ensure a focus on early intervention for carers. Good practice in this area will be transferred to other care settings.	
6.3	By December 2011, the Scottish Government will produce, with COSLA and partners, a Carers Rights Charter for wide distribution to local authorities, Health Boards, Community Health Partnerships and other bodies. By December 2013, the Scottish Government will consider whether further rights should be enshrined in law.	Carers right to assessment should include a right to a written plan for an emergency.
8.4	In 2010-11, the Scottish Government will work with the Royal College of General Practitioners Scotland on its plans to provide guidance to GP practices in Scotland on carer and young carer identification and support.	
9.1	In 2010-11, the Scottish Government will work with the Royal College of General Practitioners Scotland on its plans to provide guidance to GP practices in Scotland on carer and young carer identification and support.	

Action Points & Implementation Plan		Comments
9.2	On an ongoing basis, in order to fully engage carers and deliver improved outcomes for carers, the Scottish Government will continue to promote and monitor the use of carer outcome evaluations through Talking Points.	
9.3	In order to improve the carrying out of carers' assessments with the aim of delivering improved carer support, the Scottish Government will, by 2012, commission the production of practical guidance on the undertaking of carers' assessments. This will include guidance on how to conduct culturally competent assessments. This will be done in partnership with COSLA and NHS Scotland and will be informed by stakeholders and carers.	Include best practice in supporting carers plan for emergencies
9.4	On an ongoing basis, local authorities will monitor the impact and outcomes of carers' assessments. If any resources, supports and services are not available to meet need, local authorities will use the carer assessment process (and other initiatives) to record what is currently unavailable. This will assist strategic planning with respect to carers' support.	Consider strategic planning in relation to availability of resources to support emergency and future planning for carers
11.1	In 2010, the Scottish Government will continue to work with NHS inform on the development of its Carer Information Zone. Once fully developed, NHS inform will continually review the online service to ensure that it remains up-to-date, accurate and relevant to carers' and young carers' needs.	
11.2	By December 2011 the Scottish Government will gather and review the available evidence and scope the potential for a Scotland-wide carers' helpline and the options for providing it, including extending the service for carers offered by Care Information Scotland.	
12.1	In 2011-12, the Scottish Government will continue to provide and raise awareness amongst both professionals and the general public (including carers) of Breathing Space. The Steps for Stress booklet will be available on request	
12.2	The Scottish Government with partners, including Health Scotland and the NCOs, will produce a bespoke resource on issues relating to stress and caring, including building on Carers Scotland publication, Finding the Balance: Promoting Good Health - A Carers' Resource Guide to Health and Well-Being and linking in to the NHSinform Carers Information Zone and to Steps for Stress. The resource will be widely disseminated.	

Action Points & Implementation Plan		Comments
13.1	The Scottish Government, in allocating £1 million to the national carer organisations in 2010-11 for short breaks provision, will monitor progress towards the provision of innovative, personalised, flexible provision, which meets the needs of carers.	
13.6	For the duration of this strategy, the Scottish Government will work with a range of partners to explore the potential to develop emergency respite and to support carers with emergency planning.	Scottish Government - with partners
14.2	NHS Boards will build on the carer training provided under the Carer Information Strategies and continue to train carers beyond 2011. Subject to the outcome of the Spending Review, the Scottish Government will work with NHS Boards so that they will make a training offer to carers.	Preventative training to carers to plan for emergencies.
15.1	For the duration of this strategy, the Scottish Government and COSLA will work with local authorities, housing associations, the independent rented sector, Health Boards and other partners to ensure that the needs and views of carers are taken into account in developing more effective links between housing, social care and health policies and services.	
16.3	In 2010-12, the Scottish Government will ensure that telecare is included in the practical guide to undertaking carers' assessments and will promote its further integration within Single Assessment and Care Management/Review protocols and processes.	

Appendix 8

Glossary of Terms

Anticipatory Care Planning	Anticipatory care planning (ACP), in practical terms, is about adopting a “thinking ahead” philosophy of care that allows practitioners and their teams to work with people and those close to them to set and achieve common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome. This is particularly important for continuity of care and support should the main carer be unable to continue.
Black and Minority Ethnic Community	Any minority group who has a shared race, nationality, language and culture. House of Lords definition of an ethnic group - “Essential features are a long shared history and a common cultural tradition. There may also be some of the following present: common geographical location from a small number of ancestors; a common language; a common literature; a common religion; and, being a minority within a larger community.” An alternative definition is: “A group of people who share certain background characteristics such as common ancestors, geographical origin, language, culture and religion. This provides them with a distinct identity as seen by both themselves and others.”
Carer Information Strategy Funding	The Community Care and Health (Scotland) Act 2002 requires each NHS Board to prepare a Carer Information Strategy and the then Scottish Executive provided guidance on the minimum requirements of what these should contain in April 2006. The Scottish Government has made resources available to enable local NHS Boards to progress key actions in their Carer Information Strategies.
Change Fund	<p>The Reshaping Care for Older People Change Fund is a Scottish Government initiative that is aiming to improve services for older people by shifting care towards anticipatory care and preventative spend. The Change Fund will enable health and social care partners to implement local plans for making better use of their combined resources for older people’s services. The Change Fund will provide bridging finance to facilitate shifts in the balance of care from institutional to primary and community settings, and should also influence decisions taken with respect to the totality of partnership spend on older people’s care. Local health, housing and social care partnerships were asked to submit Change Plans in order to access the £70m available in the 2011/12 financial year. Plans were received from all 32 partnerships and were considered by the Ministerial Strategic Group (MSG). In confirming the release of Change Fund monies to all partnerships, the MSG commented that overall, partnerships had made a strong start and their Plans provide a good platform for progressing local programmes.</p> <p>Following the 2012 spending review, a further £80m Health and Social Care Change Fund will be available for partnerships in 2012/13, with £80m committed for 2013/14 and £70m for 2014/15.</p>
Community Health Partnerships	Community Health Partnerships were established by NHS Boards as key building blocks in the modernisation of the NHS and joint services, with a vital role in partnership, integration and service redesign.

Partnership In Practice	Partnership in Practice Agreements (PiPs) are agreements outlining the plans for developing and commissioning services for adults and children with learning disabilities (2007-2010).
Reshaping Care for Older People	The Reshaping Care for Older People Programme is being developed as current service configuration for care for older people is not sustainable given the demographic and financial pressure we face over the next 20 years. The Scottish Government, NHS and COSLA have embarked on a major programme to engage all interests in reshaping care and support services so that we meet policy objectives in ways that are sustainable. There is a need to look carefully at how well current services help older people to optimise their independence and well-being and to make the necessary changes.
Single Shared Assessment	Single Shared Assessment (SSA) is the approach to be used by staff for all service users who need or request help from one or more professional discipline or agency. It recognises that many people have health, social care and housing needs and that agencies must work together so that assessment and subsequent care planning are person-centered, needs-led, coordinated and effective.
SWIFT	SWIFT is designed to support the complex collaborative approach that is required for delivery of modern social care. In support of information sharing and joint working, it has the ability to integrate with a variety of external systems, ranging from corporate financial systems to education and health systems.
Talking Points	<p>This is an outcomes approach to assessment, planning & review that aims to shift engagement with people who use services away from service-led approaches. This involves everyone working together to achieve the best possible impact on the individual's life. The philosophy of this approach is one that emphasises the strengths, capacity and resilience of individuals, builds upon natural support systems and includes consideration of wider community based resources. The approach is consistent with policy priorities to engage people using services, personalisation and enablement and an assets approach to health.</p> <p>The development of the approach has involved developing a range of tools, guidance and resources to support people to work together in this way.</p>
Telecare	Telecare is the remote or enhanced delivery of care services to people in their own home or in a community setting by means of telecommunications and computerised services. Telecare usually refers to sensors and alerts, which provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards.
Third sector	The Third Sector comprises social enterprises, voluntary organisations, co-operatives and mutuals. It has an important role in helping the Scottish Government achieve its purpose of creating a more successful country with opportunities for all to flourish, through achieving sustainable economic growth.

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