

TOWARDS A CARERS' CHARTER

Introduction

Considerable work has been undertaken over recent years on the development of a Carers' Strategy for the Isle of Man and this document is intended to build on that work to provide a practical commitment for further action, rather than replicate what has gone before.

To that end, we have chosen not to reproduce the vision and mission statement that have already been agreed, and would direct the reader to existing strategic documents which can be found on the Social Care and Partner websites

This document has been produced with the support of both public and third sector organisations, and is intended as a framework which will support our journey together in developing appropriate support for those family members and friends who care for others. It will not be a static document, but, will grow and develop over time as we work together to better understand and respond to the needs of carers on the Island.

In this document a Carer is defined as someone who supports a relative, friend or neighbour who for any reason needs help with daily living, and receives no payment for doing so.

Signatories:

We hope that those partners who contribute to the Charter through its development will feel able to become formal signatories to the Charter when the final version is published.

Executive Summary

What is the Consultation about?

The consultation relates to the work undertaken by the multi-agency Carers' Executive Committee (membership contained in Annex 1) to develop a Carers' Charter.

What does the Consultation aim to do?

It is intended as a means of facilitating broader discussion on the Charter, whilst it is still in development, and we hope that all stakeholders will feel able to comment on, and be involved, as a consequence.

What do you want comments on?

The key questions for the consultation are:

1. Are the principles of the Charter right?
2. Are the key actions we are recommending within each principle the right ones?
3. Are there any further actions we should consider?

About the Consultation

The purpose of this consultation exercise is to invite comments on the draft Carers' Charter

It is not a referendum but an exercise to gather information, views and evidence to allow to the multi-agency Carers' Executive Committee take an informed decision on the final content of the Carers' Charter. In any consultation exercise the responses received do not guarantee changes will be made to what has been proposed.

How to Respond

Comments should be submitted by **5pm Friday 21 September 2012**, in writing, by post, or email to:

Carer's Charter Consultation
Department of Social Care
3rd Floor
Markwell House,
Market Street,
Douglas
IMI 2RZ

Telephone: (01624) 686208

Email: carerscharterconsultation.dsc@gov.im

Alternatively, comments may also be submitted to:

Crossroads Care
Isle of Man Carers' Centre
35/36 Derby Square
Douglas
IM1 3LW

Telephone: (01624) 673103

Email: mail@crossroadsiom.org

Electronic copies of this document are also available at:

www.gov.im/socialcare

www.crossroadsiom.org

Paper copies of the consultation document are available at:

- The Department of Social Care, Markwell House, Market Street, Douglas
- Tynwald Library, Legislative Buildings, Finch Road, Douglas
- Crossroads Care, 35/36 Derby Square, Douglas

To ensure that the process is open and honest, responses can only be accepted if you provide your name with your response. You should receive feedback on the outcome of the consultation within six months of completing the consultation.

Unless specifically requested otherwise, any responses received may be published either in part or in their entirety. Please mark your response clearly if you wish your response and name to be kept confidential. Confidential responses will be included in any statistical summary and numbers of comments received.

When submitting your views please indicate whether you are responding on behalf of an organisation.

List of persons and organisations to be consulted

- Tynwald Members
- Attorney General
- Chief Officers of Government Departments, Statutory Boards and Offices
- Local Authorities
- Isle of Man Chamber of Commerce
- Isle of Man Law Society
- Isle of Man Trades Union Council
- Isle of Man Constabulary
- Isle of Man Fire and Rescue Service
- Council of Voluntary Organisations
- Positive Action Group
- Relevant professional bodies
- Relevant stakeholders and partners, including carers
- General public

Steps which will be taken following consultation

Following consultation, the next steps in the process will be as follows:

- We will review the comments made in the process of consultation
- We will make any necessary amendments to the document
- We will formally publish the document

Headline Actions

We set out below the headline actions we will implement through working together in order to improve outcomes for carers:

We acknowledge the immense contribution carers make to society and the need for appropriate support. **We will continue to develop and implement a Carers' Charter**, consolidating existing rights and setting out key principles for carer support both now and in the future.

We will continue to help professionals in Health and Social Care, both in the public and third sectors, identify carers. We can only support carers when they and their needs have been identified. Identification opens the door to a carers' assessment and to the provision of help and support.

Taking account of the requirements of the Social Services Act, we will publish a timetable for the completion of carer's assessments/carer support plans. This will be achieved through the production of an assessment process, regulations and guidance notes to the Act, widely publicising their introduction and the carers' rights to such an assessment. Staff within all areas of Health and Social Care, the Third Sector and Day/Carers' centres will have a vital role in supporting this process.

We will improve the provision of information and advice to carers through both traditional and innovative means.

We will ensure carer representation on Strategy groups, Service Delivery Planning and other areas, which directly or indirectly affect them. Carers will be central to the planning, shaping and delivery of strategies and services for the people with care needs and in relation to support for themselves.

Carer health and well-being is vitally important as carers can suffer poor health directly as a result of caring. **We will promote and support the health needs of carers** themselves ensuring they have access to health checks and are able to avail themselves of services and treatment.

Carer training promotes carer confidence and enables carers to care for longer. **We will promote training for carers.**

The provision of short breaks or respite is hugely important to carer and cared for. **We will work with a range of partners to promote the further development of flexible, personalised care breaks.**

It is important for carers to be able to remain in or return to work and avail themselves of learning or training opportunities. **We will encourage and promote carer-friendly employment practices.**

Worries about Finances can have an adverse impact on carers' health, well-being and quality of life. **We will explore how carers' can be better informed to ensure that they receive the benefits they are entitled to and how they can be supported in managing their finances and avoiding poverty.**

There is an identified need for collaborative working between Health and Social Care services to ensure the delivery of co-ordinated services and supports. **We will work to ensure a joined up approach between Health and Social Care services.**

Housing is an important element in enabling carers to support the person they care for to live independently, safely and with dignity in their own homes and communities. **We will work to support carers in achieving appropriate accommodation.**

Young Carers are young people first whose lives are affected by care giving or caring issues we will give appropriate support to them.

Carer's Rights

We acknowledge the immense contribution carers make to society and the need for appropriate support. **We will continue to develop and implement a Carers' Charter**, consolidating existing rights and setting out key principles for carer support both now and in the future.

ACTION POINTS:

1. We will work with carer's and carers' organisations to develop the Carers' Charter.
2. We will work together and with other Government Departments and Service Providers to ensure a consistent approach to carers.
3. By December 2012 we will publish and distribute a Carers' Charter.
4. We will work together and with others to ensure wide acceptance and adoption of the Charter.
5. We will identify an appropriate multi sectoral partnership to oversee the development and implementation of the Charter.

Identification of Carers

We will continue to help professionals in Health and Social Care, both in the statutory and voluntary sectors, identify carers. We can only support carers when they and their needs have been identified. Identification opens the door to a carer's assessment and to the provision of help and support.

ACTION POINTS:

1. We will work together to highlight the role of the carer.
2. Through the Training Support Group all training events will be encouraged to integrate carer identification and awareness into their programme.
3. We will work with the Department of Health to provide guidance to GPs on identifying carers and young carers and addressing their needs.
4. Service providers and support groups will be encouraged to identify and refer carers' issues.
5. We will work to introduce a shared understanding on identifying carers and their needs.

Carers' Assessment

We will work with Government to implement the Social Services Act and progress the completion of carers' assessments/carer support plans. This will be achieved through the production of an assessment process, regulations and guidance notes to the act, widely publicising their introduction and the carers' rights to such an assessment. Staff within all areas of Health and Social Care, the Third Sector and Day/Carers' centres will have a vital role in supporting this process.

ACTION POINTS:

1. Work with those responsible for drawing up the Regulations under the Act to incorporate an assessment process.
2. Complete the assessment process bearing in mind the options available and best practice elsewhere.
3. In partnership with stakeholders and carers publish practical guidance on the undertaking of carers' assessments and publish a timescale for the implementation as soon as this is available
4. Introduce the assessment process.
5. Review the process after six months.
6. Ensure that everyone who comes into contact with carers is aware of the legal right of the carer for an assessment.
7. Publicise the new rights and encourage carers to apply for as assessment.
8. Monitor the outcomes for carers.
9. Review the process on an on-going basis.
10. Identify resources, supports and services not available to meet need.

Information

It is important for carers to have the right information and advice at the right time and we need to act to improve provision in this area. **We will improve the provision of information and advice to carers through both traditional and innovative means.**

ACTION POINTS:

Our aim is to ensure that information is:

1. Accurate – information can become out of date very quickly. Organisations must ensure literature is currently correct;
2. Accessible – easy to see and to obtain;
3. Provided when needed – on diagnosis or hospital discharge for example;
4. Provided sensitively – providers should be aware of the anxieties faced by carers;
5. Jargon free;
6. Available in various forms – for example Braille for those with visual impairment.

To be able to make informed choices carers need to know:

1. What is available;
2. Whether they, or the person they care for, qualify for help;
3. The cost involved and how this is calculated or how they may obtain assistance with the costs;
4. Who to contact;
5. Complaints procedures;
6. What they can expect from care providers in terms of service standards.

Carers Voice

We will work together to ensure carer representation on Strategy groups, Service Delivery Planning and other areas that directly or indirectly affect them. Carers will be central to the planning, shaping and delivery of strategies and services for the people with care needs and in relation to support for themselves.

ACTION POINTS:

1. To proactively advise carers of information about the illness or disability of the person they care for;
2. To develop the Signposting Service;
3. To direct carers to the Signposting Service;
4. To proactively advise carers of services available to them;
5. To make sure carers make an informed decision to take on a caring role and are aware of their right not to care;
6. To involve carers as partners in the care process;
7. To make carers feel valued;
8. To identify and respond to the needs of the carer
9. To routinely involve carers in planning and strategic development.

Health Needs

Carer health and well-being is vitally important as carers can suffer poor health directly as a result of caring. **We will promote and support the health needs of carers** themselves ensuring they have access to health checks and are able to avail themselves of services and treatment.

ACTION POINTS:

1. Work with GP surgeries, to promote the need to recognise and understand the health needs of the carer and be proactive to such;
2. Offer regular health checks to carers;
3. Encourage carers to recognise their health needs and to put in place creative and flexible services which allow them to attend appointments and undergo treatment;
4. Identify and engage with those at particular risk of preventable serious ill-health (including those with undetected chronic disease);
5. Offer carers the benefits of the seasonal flu vaccine to help protect themselves and the people they care for;
6. Introduce programmes of training for carers on person-centred moving and handling and on the safe use of equipment. This should be linked to an assessment at the point of hospital discharge planning.

Carer Training

Carer training promotes carer confidence and enables carers to care for longer. **We will promote training for carers.**

ACTION POINTS:

1. Work together to carry out a full audit of carer training currently available in order to get an accurate and up-to-date picture thus enabling a strategic view to be taken and to develop plans and funding requirements to respond to identified needs;
2. In light of that responses consider developing a Carer Training Consortium to promote and deliver high standards of training, with carer outcome evaluation;
3. Seek to ensure that all staff, working within any sector are trained to identify carers and the need for training. A well-informed, knowledgeable, trained and skilled Health and Social Care workforce is essential to help improve the lives of carers and young carers.
4. Ensure that identified training needs revealed through the carers' assessment are actioned.
5. Incorporate carer training in all Health and Social Care related strategies and action plans.

Care breaks

The provision of short breaks or respite is hugely important to carer and cared for. **There is a need for clarity over what we mean by "care breaks" and about the importance of flexible, personalised short breaks provision, leading to better outcomes for carers and the people they care for**

ACTION POINTS:

- We will work with a range of partners to promote the further development of flexible, personalised care breaks.

Finance and employment

Worries about finances can have an adverse impact on carers' health, wellbeing, employment and quality of life. **We will explore how carers can be better informed to ensure that they receive the benefits they are entitled to and how they can be supported in managing their finances and avoiding poverty.**

It is important for carers to be able to remain in or return to and avail themselves of learning or training opportunities. **We will encourage and promote carer-friendly employment practices.**

ACTION POINTS

1. We will work with Government Departments, Disability Employment Service and the Chamber of Commerce building on good practice, to promote carer friendly employment practices.
2. We will work towards carers having access to lifelong learning opportunities, further and higher education and skills development in ways which take account of their caring responsibilities.
3. We will promote the good economic and business case for supporting carers through introducing and extending flexible working practices.
4. We will seek to support carers as they begin to plan their route back into work or learning when appropriate.
5. We will seek to identify the learning, career aspirations and employability requirements of carers.
6. We will introduce regular information campaigns to ensure carers are aware of their entitlements.

Collaborative working

There is an identified need for collaborative working to ensure the delivery of co-ordinated services and supports. **We will work to achieve a joined up approach between providers.**

ACTION POINTS:

1. Ensure a co-ordinated approach is effectively established between ourselves.
2. Introduce a Memorandum of Understanding with other appropriate bodies.
3. Introduce a Memorandum of Understanding between Government Departments and Third Sector Organisations on identifying and supporting young carers.

Housing

Housing is an important element in enabling carers to support the person they care for to live independently, safely and with dignity in their own homes and communities.

ACTION POINTS:

1. We will work with the Housing Division of the Department of Social Care, Local Authorities, the independent rented sector, 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.
2. Carers' views will be taken into account in reshaping services for Older People.

Young Carers

A young carer is someone under the age of twenty-one who lives in a family where there is a serious illness or disability. This may result in them taking on the kind of responsibility that an adult would normally have, or it may affect their educational, social and recreational opportunities. **Young Carers are young people first whose lives are affected by care giving or caring issues and we will give appropriate support to them.**

ACTION POINTS:

- Seek to ensure that young carers are identified, assessed and that their families are supported to prevent inappropriate caring and support roles being undertaken.
- Educate professionals in all disciplines in the role and needs of young carers.
- Ensure that young carers are recognised and valued.
- Support young carers in a practical and emotional way.
- Ensure that young carers are supported in their transition to adulthood and to achieve their potential.
- Introduce a Memorandum of Understanding between Government Departments and Third Sector Organisations on identifying and supporting young carers.

Principles

There are a number of key principles which will underpin our work and will remain a point of reference for carers in relation to what they can expect.

We recognise that these are different in nature, and some will be easier to meet than others. As a result some elements are aspirational, but they have been agreed as the principles which drove the development of the Carers' Charter, and, as such, should be included herein.

Principle 1:

Recognising your expertise and knowledge

Your essential role and expertise should be recognised and respected.

- You should be listened to without bias or prejudice and be taken seriously.
- You should be recognised as someone who is providing support to the person for whom you care.
- You should be treated as someone who has relevant and important knowledge about the person for whom you care.
- You should be aware of the distress and anxieties that caring can cause and offer you help to cope with this.
- You should be asked to give your opinion – this should be respected and valued and where necessary, kept confidential. Where plans such as hospital admission are being considered, you and the person you care for should be given the opportunity to consider alternative care.
- Your views should be taken into account in the decisions about the person for whom you care. If you need help in communicating your views, this should be provided. You should be told how the information you provide will be used.

Principle 2:

Welcoming your involvement in care planning

You should be involved in planning and agreeing the care plan for the person for whom you care.

- You should be given a copy of the care plan of the person for whom you care (with his or her consent). This should state the responsibilities of all the people who are involved in providing care.
- You should be able to choose whether you wish to take on, or continue with the role of a carer. Carer plans should not involve you in any actions that you have not agreed to.
- Even if the person you care for is unwilling for you to be involved in planning and agreeing his or her care, you are entitled to information on the way the service works and relevant mental health issues. (Please ask a member of staff for a copy of the

Somerset Partnership's Best Practice Guidelines: Confidentiality and Information sharing with families and carers).

- You should be given information about what to do and whom to contact in times of crisis.
- If you feel that the care plan is not working or is not being properly implemented, you should be given the opportunity to state your views and to be listened to and be involved in the discussions on the action to be taken to address the problems you have identified.
- Care plans should also include how to recognise and respond to signs of relapse. Whenever possible, you should be told what to look out for and what you should do.
- When the person that you care for is receiving care and treatment in hospital, you should be involved in planning and agreeing the discharge plan, including the date of discharge.
- So far as possible, meetings should be held at a time that suits you and the person for whom you care.

Principle 3:

Responding to your needs as a carer

Your needs as a carer should be recognised, responded to, and reflected in the care plan. You should be provided with appropriate help and support. You should be told of the right to a carer's assessment

- If you have a carers' assessment, this should:
 - If you so wish, be carried out separately from the assessment of the needs of the person for whom you provide care.
 - Allow you to have someone to support you while the assessment is taking place.
 - Give you the opportunity to assess your own needs.
 - Assess your needs without the assumption being made that you are willing or able to take on a caring role or to continue to provide the same level of care.
 - Consider how your caring role affects your relationship with other family members and friends and your ability to hold down a job.
 - Address your own health and well-being, your need for emotional and other support and how you would like to be helped in providing care.
 - Consider whether you would like to take a break from caring and if so, look at what type of support you think would enable you to do this.
- You should be advised on what action to take if you are not happy with the assessment or the decisions made as a result of the assessment or if you think that the care plan is not being implemented properly.
- All staff should recognise that you may have additional commitments to that of your caring role, such as looking after your children or going to work.

- Your personal characteristics should be respected and taken into account and you have the right to be treated without prejudice.
- The information that you are given should be clear and accurate.
- The information should be provided in a way that is helpful to you – for example, orally, in writing or on tape, in your own language, through an interpreting service or in discussion with a qualified professional.
- You should be told about opportunities to take a break from caring.
- You should be given the details of local support groups and advocacy services.
- You should be helped to get advice about housing and any employment issues, financial matters, including entitlement to benefits and training for carers.
- You should be given a copy of your own care plan in a form you find useful.
- The services that you receive should be of a good quality, appropriate to your needs and provided within an agreed time.

Principle 4:

Valuing your involvement in service development

You should be given the opportunity to be actively involved in the planning, development and evaluation of services.

- You should be given the opportunity to state your views on the quality of the services provided and on the range of services which need to be developed.
- You should be told how your views will be taken into account as part of an on-going evaluation process.
- Where you are invited to meetings where you can contribute to the planning, development and evaluation of services, you should be offered help in arranging alternative care for the person you care
- You should be told how the information you provide will be used.