

Caring for our Carers: Supporting unpaid carers in the British-Irish Council Administrations



Ministerial Introduction

The Scottish and Welsh Governments have jointly chaired the British-Irish Council (BIC) Social Inclusion work sector since its establishment in 1999. We are delighted to present this latest Report which focusses on carers and the families and friends of people who need support to live meaningful lives. As our societies change, we must develop our policies wisely and creatively to promote the rights of carers, prevent their loneliness and isolation and support the development of carer-friendly communities.

This Report provides an important and encouraging contribution to the evidence about how we support our carers at the various stages of their caring journeys. It contains service examples and case studies which describe the benefits brought to the lives of carers and those supported by them. At the Social Inclusion Ministerial held in 2015, Ministers agreed to look at how best we could support carers across the eight Administrations. This report gathers together examples of best practice, new policy initiatives and community engagement from all the members of the British-Irish Council. Five broad thematic areas have been identified for these examples:

Carer Identification which helps our administrations identify carers so that they can receive the support that they need.

Supporting young carers in both community and school based schemes to ensure that they can develop personally, socially and educationally while also carrying out their caring role.

Supporting older carers and carers of older people to address the demographic shift which will see a

greater number of older people in the coming years both requiring care themselves and providing care to the elderly.

Caring skills, self-care and technology-enabled care which gives an overview in how individuals can improve their abilities to take care of both themselves and others through training or the provision of new technologies.

Bereaved Carers as those who provide care often need specialised support to assist them in dealing with the loss of the cared-for person.

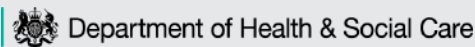
We all want to support carers in their important role, looking after their loved ones in communities they feel connected to, for as long as possible. BIC Social Inclusion Ministers will use this Report to support our efforts to meet these key challenges in the years ahead. The examples identified and analysed in this report add to the deep well of shared learning between all eight of our administrations which is at the heart of the work of the British-Irish Council.



Aileen Campbell MSP, Minister for Public Health and Sport
Scottish Government



Huw Irranca-Davies AM, Children and Social Care
Welsh Government



Carer Identification

Identifying carers presents complex challenges. Each case is different with a wide variety of factors involved. The BIC Social Inclusion work sector has attempted to address some of the challenges faced in this area through open engagement between policy leads in each of the eight administrations to highlight effective measures to identify carers.



Carer Positive employee

Being identified as a carer is often the first step which enables someone to receive the care and support that they need. Once a carer is identified, they may be able to receive emotional and practical support, access a break from caring or to pursue other opportunities such as sport and leisure. They may also receive help to overcome any inequalities that may arise as a result of their caring role, such as in their employment.

In identifying carers it is important to recognise that there is no set path or timescale for becoming a carer. The role of the carer is likely to become more apparent as the person they care for becomes older or more unwell. In some cases a person's caring role may evolve and gradually

increase as the condition of the person they care for gradually deteriorates. In other cases, an individual may become a carer overnight if their loved one has a neurological event, such as a stroke.

Some individuals may not identify themselves, or wish to be identified publicly, as carers. In some cases the individual may not be aware, or may not yet wish to recognise, that they have become a carer. In other cases, the individual may be aware that they have caring responsibilities but are not aware that they may be eligible for support as a result. It may be the case that they do not wish to seek support. In some cases, for example substance misuse, there may be a fear of societal stigma if a person is identified as caring for a loved one with this type of issue.

Carers will also interact with and come to the attention of the system in different ways. They may come into contact with health and social care professionals, either on their own account or through the person they care for, while young carers may be identified through education.

A range of possible routes and approaches for identifying carers is needed in order to respond to this complexity. The examples in this section illustrate some of the different approaches adopted across different BIC administrations.

1	Family Action - The Bridge Young Carers Neighbourhood Charter - UK Government	Page 4
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1 Family Action - The Bridge Young Carers Neighbourhood Charter - UK Government

Overview:

Family Action delivers a county wide young carers service in Durham, known locally as The Bridge, for children up to 18 years of age. The model aims to improve wellbeing, strengthen relationships and reduce inappropriate care giving. Services are delivered according to the level of need, providing specialist family support and targeted support to children and young people, as well as administering family and community grants.

Since 2011, The Bridge has developed and delivered an Early Help support pathway for young carers, known as the Young Carers Charter. The Charter aims to ensure young carers are identified and supported at the earliest opportunity, and that there is no “wrong door” for a child or young person with a caring responsibility.

Family Action has now developed a neighbourhood version of the Charter to bring it into the local community.

How does it work:

The Young Carers Charter acts as a change agent by influencing and embedding best practice which is absorbed into everyday culture and practice. Family Action checks that schools have met the elements of the charter before award, and after two years schools have to complete re-accreditation.

The Neighbourhood Charter was developed using learning from the Young Carers Charter; working with children, young people and the community; and was aimed right at the heart of the community, with voluntary and statutory services working together.

Those wishing to gain Charter status are required to:

- undertake an audit within their school, organisation or group;
- participate in a young carers training workshop;
- provide evidence against specific pledges of support that were developed with Young Carers.

What has been the impact:

Since the work started, there is evidence of growing numbers of young carers being identified and supported. The approach ensures that Young Carers are on everyone's agenda and are everyone's business.

“The Young Carers Charter will help with the recruitment of the Prince’s Trust 12 Week Team Programme in Bishop Auckland and Darlington. Additionally, it will help the tutors have a better understanding of the challenges that face young carers and how we can work to support them on our programme”

Matthew Wigmore, The Prince's Trust



“Having the charter is already impacting on our group in a positive way. The notice board is placed in the room that we do most of our youth group work; so now the young people have access to information at any time they need it. It has also sparked conversations and got the young people talking about the charter and young carers”

Lucy Mann, Youth Worker, St John's Church

2 Investors In Carers Scheme - Welsh Government

Overview:

A Welsh local health board is working in partnership with local authorities, the Third Sector and with the GP surgeries to implement the Investors in Carers scheme. As part of the liC scheme, GP surgeries encourage Carers to come forward and register themselves as Carers. A registration/consent/referral form is now available in each county for this purpose. The Carer has the choice of registering themselves as a Carer at their surgery. This can lead to the surgery making some allowances because of their caring role, e.g. flexible appointments. However this depends on the capacity of each surgery.

There are three levels this scheme accredits: Bronze, Silver and Gold. The Bronze level sets out what should be done for Carers at a basic level. The Silver level is about outcomes and results and the differences they make to their Carers lives. The Gold level is where GP surgeries need to meet a number of requirements including maintaining an up-to-date Carer's Register, have a Carer's Lead, provide flexible appointments for Carers and hold a minimum of one Carer's clinic per year.

A by-product of the IiC scheme has been the development of a Carer Lead. This person takes the lead in the setting (GP Surgery, Pharmacy etc) who is the contact for the Carer, helps the Carer get registered and referred to other help and support. There is an annual event for these Carer Leads so they can learn and improve their help and support to Carers.

What has been the impact:

The IiC scheme continues to be applied by all GP surgeries within the health board area. The IiC team have been supporting surgeries to meet their objectives on the Carer agenda with the great majority of surgeries (98%) having gained the Bronze level standard.

A number of surgeries are now working on the Silver level - a more advanced level that demonstrates new (or more in-depth) ways of working to support Carers.

The IiC team are helping GP surgeries and Carer Leads to work more closely with some of the voluntary sector organisations including Marie Curie, the British Red Cross and the Alzheimer's Society. A guide and toolkit

has also been produced to help surgeries with ideas on how they can help Carers further and achieve this level. This includes offering annual health checks and measuring the differences these make to Carers; working more closely with District Nurses to help identify 'hidden' Carers and measuring the impact of this exercise.



Nine Community Pharmacies have gained their Bronze level in total with a further 10 engaging with the scheme.

Most GP surgeries (and Community Pharmacies and other settings) have now identified a Carer Lead. This person's role is to be a point of contact with the liC Team, receive Carers' information and cascade this to the rest of the staff. Other duties include keeping their Carer notice board up to date, supporting national and local events as well as speaking with Carers about their circumstances and signposting them as appropriate.

Three schools in the health board area have also achieved their Bronze level. A further five schools are currently working towards their accreditation. The number of carers recognised and registered has increased as a result of the project and the number of staff working in GP practices receiving training to recognise carers and their needs, has increased.

A Practice Manager for a GP Surgery commented: *"The Surgery is proud to accept the Silver award in recognition of our commitment in supporting Carers of all ages. We have attended many local events to gain knowledge of services available for our registered Carers."*

Another Practice Manager for a GP surgery added: *"We are delighted to have received the Silver level award – we hope this reflects the importance we place upon identifying and supporting Carers."*

Boots said: *"Taking part in the Investors in Carers Scheme has definitely helped us to support Carers. We have found out about the extra support that we didn't realise was there."*

"Working in a community pharmacy gives you direct contact with people enabling you to have a conversation and reach out to people who aren't looking for help but it becomes apparent that they could do with it. I can help people find out about the kind of support there is out there, it is important for people not to be nervous of it – they can often be worried about asking."

Carer Story – *"My husband has been diagnosed with early-onset Vascular Dementia and it took me quite a few visits to my GP surgery before I realised I was a Carer. I had read the information several times before I realised that it applied to me. I have registered with my surgery and have found the information pack I received very useful. I have met the Carer's Outreach Support worker who was very helpful and attended a support group which was the last thing I thought I wanted to do but in fact have found it very useful"*

"I realised that I was a Carer and could register with my GP after seeing the notices on the board in my Surgery."

3 Carer Positive Scheme - Scottish Government

Overview:

There are an increasing number of carers in the working population in Scotland. As many as 1 in 8 of the workforce are thought to be juggling work and caring responsibilities.

Research has shown that caring roles can limit people's employment opportunities and access to career development, promotions and pay rises. Caring can also affect carers' ability to work at all. As many as 4 out of 10 carers (43%) said they had given up work completely to care, with 13% reporting that they had retired early to care.

Carers and employers both benefit from carer-friendly workplaces, which can help improve the recruitment, retention, and resilience of staff.

The Carer Positive initiative was developed through a wide ranging consultation and launched in 2014. It is funded by the Scottish Government and co-ordinated by Carers Scotland.

Carer Positive aims to raise awareness of the growing number of carers in the workforce, promote the business case for employers to support working carers, and award recognition to those organisations with good practice in this field.

How does it work:

The Carer Positive award incorporates three levels, from 'Engaged', to 'Established', through to 'Exemplary'. Employers can progress from one stage to the next, building from an initial level of commitment to embedding a culture of support for carers within the organisation. There is no cost associated with participating, and the application process is designed to be clear and straightforward.

All employers, whether small or large, can achieve each level of the award, and are encouraged to identify and develop their own actions and policies as appropriate to their size and structure. This helps to identify and support carers across the labour market spectrum.

To become recognised as a 'Carer Positive employer', organisations submit an application which describes how they support carers across five key areas:

identification; policy; practical support; communication; and peer support. Evidence of good practice is gathered via the application form. Good practice can include flexible working conditions, work-life balance policies, carer leave, carer employee networks and signposting to local carers centres and external support. Sometimes good practice is well established and in other cases it may be developed as a result of the application process. Applications are assessed by Carers Scotland and successful organisations receive the Carer Positive Employer logo, a framed certificate, and workplace posters.

Identification is a key starting point in developing support for carers – it enables employers to have a better understanding of the carer population in their workforce, and helps people to identify themselves as carers when they might not have otherwise done so.

Existing Carer Positive employers use different methods of identifying carers. Examples of good practice include carers registers, carers passports, employee surveys, carer awareness sessions and induction training.

What Has Been The Impact:

Just over 100 organisations have been recognised as 'Carer Positive employers'. These employ around 300,000 people across Scotland. They include local authorities, health boards and other public bodies, utility companies, further and higher education institutions a range of voluntary sector organisations, private companies and small and micro-employers. Over 25% of those organisations have progressed within the scheme to the 'Established' and 'Exemplary' levels of the award.

Feedback from employers has been positive. Many report that the framework helped them take stock of their current position and identify the areas where they needed to take action and develop support. Although the scheme has not yet been formally evaluated, there is anecdotal evidence of the uptake of support as a result of carers policies and of positive impacts for both employers and carers. This includes, for example, reports of reduced absence levels as a result of introducing carers leave policies.

Testimonials from carers are collected as part of the application process. Many of these confirm the importance to them of recognition and support from their employer and the difference this has made in enabling them to remain productively in employment.

"It is important for me to be able to work at an organisation which has a carers policy in place. Not only does it make me feel more at ease and more confident about being able to concentrate on my work and be productive, it also assures me that there is flexibility where needed. I am glad they have taken this official step to be more visible about it as it may also encourage more people to come forward and talk about their own situation and get help. Furthermore, it proves to me that the organisation has a human interest in assuring their staff are looked after, which I think is invaluable."

An employee of a Carer Positive organisation



West Dunbartonshire Council are awarded Carer Positive status, March 2018



"The organisation has made an enormous difference to me as I have tried to juggle my roles as an employee and an unpaid carer. Without these policies and the practical support I have received, I would have found it impossible to continue in my job for as long as I have. Because my needs, and those of the person I care for have changed I am presently taking a career break but this would not have been possible without NHS Lothian's support. I am confident that as and when my situation changes again I will continue to be positively supported."

An employee of a Carer Positive organisation

"The Scottish Court Service is committed to providing support to its staff who have significant caring responsibilities. We need to retain staff who are skilled and experienced in court procedure and providing help through our carers policy to achieve a good work life balance makes good business sense. Carers are often remarkably positive people who bring great organisational skills into the workplace."

The Scottish Court Service, a Carer Positive employer

"At Wheatley, we aim to be a supportive and inclusive organisation. We recognise that many of our employees have caring responsibilities at home, so any best practice we can implement to support our carers will benefit both us as an employer and our employees. We are delighted to be recognised as an early adopter of the Carer Positive Award."

Wheatley, a Carer Positive employer

Young Carers

Pages 10-20

Young carers play a vital role in many families but a young person's personal and physical development, physical and emotional health, education and social opportunities can all be affected by having a caring role. As part of the British-Irish Council Social Inclusion work sector focus on carers, officials from all eight administrations have met at various stages in the last two years with young carers to discuss their experiences and insights.

Caring roles can place stressful responsibilities on young carers at home, reducing the chance for them to be children first and foremost. Caring roles can affect young carers' experience of education, increasing stress, affecting attendance and reducing the time available for study, with potentially negative effects on their academic progress. Caring roles can also isolate young carers from their peers, for example by making it more difficult for them to participate in sports and other leisure activities. These experiences in childhood can have profound effects on young carers' health, development and opportunities in later life.

Better awareness and early identification of young carers, together with provision of support in both school environments and community-based settings, can all help to improve quality of life and life chances for young carers. During a visit to the Isle of Man in 2017, for example, members of the Crossroads Care group spoke to BIC officials about a project where children who are caring for a parent or sibling, often as a primary carer, are given some space and time to be themselves.

Increased awareness of young carers in their communities, and support for young carers and their families can allow these young people to build confidence and grow and develop beyond their caring role. By identifying them, and focusing on their importance, the wider community also becomes more aware of them and the role that they undertake. By understanding and increasing awareness of young carers, schools can counteract any detrimental effects of this caring role. As more young carers are recognised in the classroom by

peers and in the training of their teachers, the benefits for their schoolwork and mental health can be significant. It is recognised that where young carers are appropriately supported, their experience of caring can be a positive one.



The examples in this section illustrate a range of different approaches to supporting young carers to ensure they can be children first and foremost and can have the same opportunities as their fellow young people alongside their caring roles.

Community Based Projects

1	Young Carer ID Cards - Welsh Government	Pages 10-11
2	Crossroads Young Carers - Isle of Man Government	Pages 12-13
3	Family Action Islington - UK Government	Page 14
4	My Time for Young Carers - Jersey Government	Pages 15-16

School Based Projects

5	Supporting Young Carers in Schools Booklet - Northern Ireland Executive	Pages 17-18
6	Stirling Young Carers Project - Scottish Government	Pages 19-20

1 Young Carer ID Cards - Welsh Government

Overview:

Supporting Young Carers in Schools: A Step by Step Guide for Leaders, Teachers and Non-teaching Staff is a guide and toolkit written in association with teachers and school staff based on the work of Carers Trust and the Children's Society in England. This resource helps to make the identification and support of young carers in primary and secondary schools, as easy as possible in Wales.

The step-by-step guide forms part of the Young Carers in Schools programme, a free England and Wales wide initiative to make it as easy as possible for schools to support young carers. Carers Trust Wales have adapted the programme in Wales, developing a step by step guide to:

- ensure young carers are not being overlooked in schools.
- provide a national approach to support teaching, learning and awareness raising in schools.
- work alongside the development of the Successful Futures curriculum, ensuring the programme provides an integral approach to supporting vulnerable learners, of which young carers make up a large majority.
- provide a real opportunity for joint working with health, local authorities, young carers, their families and young carers services.

The Young Carers in Schools programme was successfully piloted by 8 schools in Wales (in Gwynedd, Denbighshire, Conwy, Pembrokeshire, Merthyr Tydfil and Caerphilly). The Minister for Children and Social Care launched the toolkit at an event on 6 December 2017 to promote awareness of this excellent resource.

How it Works:

By taking part in the Young Carers in Schools programme, schools will have access to:

- This Step-by-Step Guide: making it as easy as possible to identify and support young carers;
- Tools: including templates, proforma and exemplars accompanying each step; and

- Additional resources: offering a growing library of online materials to support learning, training and progress in relation to the Young Carers in Schools programme across England and Wales.

The Young Carers in Schools programme enables schools to:

- Demonstrate to Estyn that their school is meeting the needs of young carers, specifically mentioned in the Inspection Guidance¹, 2016.
- Identify manageable steps to improve educational outcomes for this vulnerable pupil group – the programme breaks down the actions schools can take so that their school can prioritise what to do next.

The Step-by-Step Guide sets out ten key steps to implementing the effective identification of and support for young carers in schools, including setting up systems to identify, assess and support young carers and raising awareness of school staff about young carers.

Like other aspects of school life, the development of effective support for young carers is reliant on regular reviews of current provision and the identification of areas for continual improvement. The steps are therefore a cyclical process, which schools should engage with throughout the school year.



¹www.estyn.gov.wales/inspection/inspection-guidance

Impact:

The Step-by-Step guide and toolkit supports schools that have been developing systems to identify and support young carers over many years to enable the schools to spot any gaps in provision, get the most out of resources and maximise the impact of work. It also supports schools that are developing or just starting to develop their provision for young carers – helping them to prioritise what to do next, so no school needs to start from scratch.

Pilot schools in Wales have seen a significant increase in the number of young carers identified since the being of the programme. The pilot has also highlighted the importance of wider young carers services and the relationships between them - schools, social and education services within local authorities, health professionals and the third sector - in supporting the well-being of young carers.



Kathryn Evans, Headteacher of St Gwladys Bargoed School comments:

“The plight of Young Carers has been a central concern for many years but engagement with Carers Trust Wales has provided a far clearer and more focused direction. Consequently, we have identified a number of young children who are in this vulnerable position and become far more aware of the plight of sibling Young Carers. Importantly, the school has developed a more cohesive response as a result.”

“Because of the Carers Trust Wales initiative, staff are clearer about what action to take and the appropriate support available. This has enabled the school to direct families to the correct services and avenues of help.”

“There is no doubt that the Carers Trust Wales programme has already proved to be of significant benefit to the young people concerned.”



2 Crossroads Young Carers - Isle of Man Government

Overview:

Young Carers is a project specifically built around taking the carer away from their care responsibilities. The project has been running on the Island for 18 years and in that time has provided groups and individuals with access to support.

The project recently expanded to include young adult carers up to the age of 24 years as it was found that young adults with care responsibilities between 16 and 24 were in danger of slipping through the net of support and becoming categorised as NEET "Not in Education, Employment, or Training".

How does it work:

Fortnightly sessions give children who are caring for a parent or sibling, often as a primary carer, some space and time to be themselves. Activity trips on and off Island and work within education underpins this valuable scheme.

What has been the impact:

Substantial evidence that support of young carers enables them to continue to care, and to access mainstream education services and work opportunities.

"I love coming to Young Carers. We have lots of fun and I get to do things that I can't do with my family as my brother doesn't like noisy places."

Young Carer aged 8

"If I want to talk about what's going on at home I can. The staff ask about me and not my sister- everyone always asked my Mum how she is."

Young Carer aged 10

"I love seeing my best friend on Young Carers, we'll be BFF's for life!"

Young Carer aged 13

"I've really struggled being a carer for my Dad and brother and it's nice to talk to people that understand."

Young Carer aged 18

"The staff are lovely and my children always come home with massive smiles."

Parent of a Young Carer

"My son has had so many changes in his life and Young Carers has always been the consistent support to him"

Parent of a Young Carer

I can't thank you enough for taking A the other afternoon for a couple of hours. I was at my wits end and it made a huge difference"

Parent with a disability



Young Carers Day at the Venture Centre Gorge walking and coasteering



Young Carers Day at the Venture Centre Gorge walking and coasteering



Young Carers volunteering at the Wildlife Park selling cakes, making crafts and all thing spooky!



Douglas Carnival 2017, dressed as superheroes as we think Young Carers are heroes!



A print workshop ran by a local artist



Art work by a nine year old Young Carer- the hands are Crossroads helping hands



More arts and crafts during a session

3 Family Action Islington & Camden Young Carers Service - Building Stronger Families - UK Government

Overview:

Family Action's Islington and Camden Young Carers (ICYC) service works with the whole family to look at ways of supporting the young carer and the person in need of care. The service recognises that if we are to improve outcomes for young carers by reducing their caring role, direct work must be done to empower and ensure change for those who require care.

An important element of the local young carer's strategy is to improve identification and recognition of the needs of young carers, and to improve working across services in relation to need. The aim is to facilitate change within teams and services by equipping professionals with the knowledge and skills to be able to identify and respond to need. In line with this, ICYC have developed a range of outreach resources and delivered workshops.

How does it work:

Following an initial assessment, a support plan is agreed with the family, which will include external services and professionals where required, ensuring a multi-agency approach is adopted. The plan will combine practical and emotional support to address needs. ICYC aim to work with families for up to six months.

Safeguarding young carers is at the heart of this work. ICYC utilise their young carer and parental assessments to contribute to the completion of an early help assessment. They also use specific outcome tools developed by Joseph, Becker and Becker (Manual for Measures of Caring Activities and Outcomes for Children and Young People 2009) to support them to quantify the caring role and its emotional effect, as well as ensuring that the impact of this work can be measured.

What Has Been The Impact:

Outcomes over the past year have included:

- Reduction of the caring role undertaken in 66% of cases.
- Improved school attendance in 58% of cases.
- Reduction of the negative impacts of caring in 78% of cases.
- Increased self-esteem in 62% of cases.

"They let me say what I want to say, it's a lot less interrogation. A lot of professionals try and tick a box in what they ask you but they (Family Action) really listen to you and they really care."

Quote from a Young Carer supported by Family Action's ICYC

"I was able to talk about issues, very important as there were lots of issues and feelings of isolation. I felt relaxed, listened to and supported and it gave me my self confidence back. They took the time to build a relationship with the children and we have had all the help we have asked for"

Quote from a Parent supported by Family Action's ICYC



4 My Time for Young Carers Jersey Government

Overview:

My Time for Young Carers is a project of the Jersey Youth Service. My Time works to deliver on the Youth Service promise to provide young people with:

- Opportunities – that include a range of activities, events, courses, support, and information.
- Places – that are welcoming, safe, well equipped and well-staffed.
- A voice – so that they can have a say, get involved, be heard and make a difference.
- Equality – to be treated fairly and valued as an individual.

How it Works:

My Time for Young Carers works to create a needs assessment process to help identify young carers and their on-going needs. The project aims to:

- Ensure young carers in Jersey are recognised and valued;
- Give young carers a voice;
- Raise awareness of young carers, to support and influence change;
- Increase the support available to young carers;
- Take on an integrated approach with schools and other agencies to meet the needs of young carers;
- Provide access to new opportunities and experiences;
- Refer/signpost young people to other agencies or services as and when required.

My Time for Young Carers provides young carers with the time and space to be young people and have fun. They run weekly activity sessions, which include: cooking, climbing wall, crafts and dancing. The project also organises various trips and residential stays which provide opportunities for young people to have new experiences and build skills.

Holiday programmes are organised to allow a social space when the young carers are not at school, as well as the opportunity to take part in a range of fun activities to make the holidays memorable.

The project works with schools and other organisations in the Island to support, advise and guide them on the needs of young carers and how to best identify, support and work with young carers in the community.

My Time is dedicated to raising awareness for young carers with an Island-wide awareness day, assemblies at schools, awareness stands at community events as well as providing informative promotional material across the Island.

It is important to provide young carers with a voice in the Island and the project ensures that young carers are consulted on all matters and encourages them to be involved as much as possible. For example, the young people created the My Time logo and promotional material with the help of a youth worker and a graphic designer, as well as being involved in the creation and delivery of presentations. Working in this way is giving young carers a voice and empowering them to make a difference in their Island as well as building their skills and confidence.

The project is co-funded through a local grant making organisation and funding from the Government of Jersey.

What has been the impact:

The project has provided support and advice to young carers and their families. It has helped to build the confidence of young people and provide opportunities for them to grow and develop beyond their caring environment. The project has also raised awareness of the needs of young carers within the wider community.





Family 1

“My Time has helped my child to have their own time where they can talk if needed and build confidence.

My Time has helped me know that they have some good times, as it is always about their sister and not them outside of My Time. I don't have to worry about them for one night.

My Time is a way that they can be themselves and have fun, away from the day-to-day family life that can bring them down.”

Family 2

“My Time has helped my child to have their own time and be with other young people who are going through the same thing that they are. My Time gives me time to have one-to-one time with their siblings and it helps my child socialize.”



5 Supporting Young Carers in Schools Booklet - Northern Ireland Executive

Overview:

Young Carers are defined as children and young people aged up to 18 years who have a substantive caring role for a member of their family or those whose health or development are affected due to that caring role. A Young Carer's personal and physical development, physical and emotional health, education and social opportunities can all be affected by their family situation and their caring role.

At least 10% of 16 year olds could be helping to care for a family member, providing up to 30 hours of care a week and 29% of these young carers have never told anyone outside their family about their caring responsibilities. These young people usually feel stressed, tired and isolated.

To better support Young Carers in school in Northern Ireland and to raise awareness of their needs among educators and teachers, the Children and Young People's Strategic Partnership Regional Young Carers Group have produced a resource pack for primary and secondary school staff. This publication builds on and develops principles and tools from a resource published by Carers Trust Northern Ireland – Carers Trust (2013), Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff (Carers Trust UK). Thank you to the original contributors. Some of the information in this publication has been taken and/or adapted from this earlier resource.

The organisations involved in this initiative were the Health and Social Care Board in partnership with the Education Authority, Action for Children NI, Barnardo's NI, Gingerbread NI and Carers Trust NI

The Children and Young People's Strategic Partnership, led by the Health and Social Care Board, is a multi-agency partnership that includes the leadership of key statutory agencies and community and voluntary organisations that have a responsibility for improving the lives of children and young people in Northern Ireland.

The Supporting Young Carers in Schools Booklet will make young carers more visible and help teachers to better meet their needs. The booklet is a positive example of co-production between education and health & social care authorities; between the agencies helping young carers; and between the various organisations and young carers themselves.

How it Works:

The Education Training Inspectorate in their Report of a Survey of Vulnerable Children and Young People 2006-2007 states that 'Schools are remarkable places where the whole staff team work diligently to support and encourage the learning of children and young people not only in terms of their educational needs but also their social and emotional development. Teachers have a responsibility to provide a safe, structured and consistent environment for the children and young people in their class with a strong emphasis on pastoral care'.

The preparation of this guidance through the interagency Children and Young People's Strategic Partnership Regional Young Carers Group is a continued tradition of collaborative work and has been developed with the help of 23 Young Carers who attend the Regional Young Carers Service funded by the Health and Social Care Board since 2007. The booklet is intended to help staff in schools increase their awareness of the caring role of a Young Carer and how best they can be understood. It also offers school staff practical strategies to adopt in school and identifies external support that is available to support Young Carers in education.



This guidance provides schools with specific guidance to support young carers effectively. The document provides school staff with a step by step framework for support in school including;

- Ensuring pastoral processes are in place for the individual in the school;
- Ensuring appropriate access to professional counselling support in school;
- Assigning a school lead or network of support for the Young Carer in school;
- Amendments to school policy to reflect the extent of duties for Young Carers;
- Establishing a clear communication plan between school and home.

What has been the impact:

- Staff across agencies are better informed about the step by step process to support young carers across primary and post primary education in Northern Ireland.
- Increased awareness raising in schools of the role of young carers and the needs they may face with practical ideas and strategies for school staff to support young people.
- Young Carers highlight a more positive school experience now that teachers have been able to understand the extent of their caring duties and support them in their education. One young carer who has been receiving support from the Regional Young Carers Service has said “Finally admitting to my teacher what was going on at home was the bravest thing I’d ever done, after that, things finally changed for me”.
- Promotion across 7 partner agencies; online promotion on Education Authority, Health and Social Care Board, Action for Children, Barnardos NI and Children and Young People’s Strategic Partnership websites.
- The booklet has been circulated through the education sectors C2K network to primary and post primary schools through Education Authority.
- Through promotion of the booklet via social media outlets including Twitter and Facebook the booklet has reached over 22,043 people since September 2017.
- Education Authority Chief Executive, Gavin Boyd -

“The Education Authority is proud to be a partner in this initiative to help schools understand the needs of young carers and to enhance the support provided to children and young people who have caring responsibilities. The young carers who were involved in the development of this resource are undoubtedly helping to make things a little easier for others who find themselves in similar circumstances to theirs.”

Fionnuala McAndrew, Director of Social Care & Children, Health and Social Care Board HSCB

“I am particularly pleased to note that this work has been done in collaboration with the children and young people who use the service. When CYPSP was established we were determined to see participation of children and young people as being at the heart of what we were trying to do. I would like to thank the agencies from the statutory and voluntary sector involved in the preparation of this document. I hope this guidance is helpful for all those who support young people in education and we look forward to continuing to work together to address the needs of young carers.”



The booklet is accessible from;
www.cypsp.hscni.net/wp-content/uploads/2017/08/Supporting-Young-Carers-In-Schools-Booklet-Final.pdf

6 Stirling Young Carers Project - Scottish Government

Overview:

During the preparing the Forth Valley Carers Strategy, Stirling Young Carers Centre interacted on an individual level with many young carers in the area. A significant number of these individuals identified a range of issues such as transition from school, bullying, educational attainment and emotional difficulties that were affecting them as a consequence of their caring role. Stirling Young Carers is funded by ‘The Big Lottery’.

Stirling Young Carers Centre identified that schools are one of the best places to identify and support young carers, and play an important part in combatting many of the identified issues.

All 47 schools in the Council area have signed the Stirling Young Carers Project Charter, and each school has a Young Carer Schools Coordinator who provides the link between school and Stirling Young Carers service.

How it Works:

The project undertakes numerous strands of work, raising awareness of young carers to school staff and pupils and supporting young carers, including:

- a young carer designed poster with information on identifying young carers, which are displayed in staff lounges;
- continuous professional development designed to raise awareness of young carers delivered to teaching professionals via workshops or through attending in-service days;
- a DVD developed to show professionals the issues young carers may face;
- the ‘Young Carers Class’ – a school period held once a week available to all young carers in each school run by the school to support them with support and valuable life skills. All schools in Stirling now have a Young Carers Class facilitated by the project, school or as a partnership;
- school professionals now update the pupil registry system, SEEMIS, with individual pupil information so all teachers are aware of young carers within their classes;

- a meeting with senior management team in every high school to highlight the issues faced by young carers – this allowed for the establishment of a framework of support;
- awareness raising sessions in 2016 to 32% of the school roll to raise awareness of young carers.

What has been the impact:

The project recognised that a ‘one size fits all’ approach would not be appropriate and schools needed to work with young carers on a personal and tailored basis.

This project helps to reduce the stigma and identify ‘hidden’ young carers. It also helps to increase awareness among all teachers and pupils, ensuring a level of consistency in identifying and supporting young carers.

The project has seen a marked improvement in the attendance levels of young carers, their attainment and overall behaviour and young carers have reported positive outcomes.

Following implementation of the project, young carers from one school in the area fed back that:

- 90% felt less stressed
- 100% felt more supported in school
- 80% had improved their school attendance
- 100% felt less isolated
- 90% felt they do better in school

The project also received international recognition by being highlighted as a good practice example in a conference in Europe, in particular for their work at a local high school and their ‘Young Carer Class’.

Case Study

Billy, aged 15, is a young carer at a local Stirling High School. He cares for his older brother Joe who struggles with his mental health.

Joe's behaviour can be fairly erratic and can cause Billy and his family a lot of stress. Unfortunately, Joe is in and out of hospital and Billy worries a lot about his brother, particularly while he is at school.

Billy's school referred him to Stirling Young Carers Service where he receives group support and is able to meet with peers facing similar issues.

This has really helped with Billy's confidence, however Billy still worries about his brother a lot. His school acknowledged that his Pupil Support Teacher may not always be available to speak to Billy about the impact

of his caring role, particularly if he is struggling with homework or cannot concentrate in class. As a result, Billy was offered a mentor that he can talk to and who would also be available to provide support as and when required.

Billy often catches up with his mentor, particularly if things have been stressful during the night and finds this very helpful. All young carers in his school now have a mentor who understands their caring role and the impacts it may have.

Billy also attends his school's Young Carer Class once a week, which is run by the school in partnership with Stirling Young Carers Service. This allows him to spend time with other young carers in his school in a safe environment and learn valuable life skills too.



One of the key priorities for action identified and agreed by the carers work stream is the care and support we provide for our Older Carers and carers of older people.

Throughout the jurisdictions of the British-Irish Council Members, there is an ageing population and attendant rise in prevalence of chronic and life-limiting conditions. This, alongside a shift towards care in the community means that there will be a greater number of older people in the future needing care and, as a consequence, an increasing number of older people in caring situations (older carers). There will also be an increasing number of younger carers of older people. In many instances, older carers will also have care and support needs of their own, while younger carers of older people may also be in paid employment and raising children (the so called 'sandwich generation'). It is important that we do not underestimate the impact that caring can have on the mental, emotional and physical health and well-being of these individuals.

In addition, older carers have to face serious concerns about what will happen to those they care for when they are no longer able to provide that care in the future. This may particularly be the case for the ageing parents or siblings of an adult child with a disability. A proactive approach to succession planning and planning for the future is therefore vital to ensure continuity of care and to support the carer to sustain their caring role.

Older carers frequently find themselves in mutual caring situations, e.g. in the case of a carer with dementia who is both caring for and being cared for by a spouse with physical health conditions, or an elderly parent caring for and being cared-for by a son or daughter with a disability.

The number of people with dementia is rising in all of the jurisdictions. Caring for a loved one with dementia often involves long hours of care and can

lead to social isolation for both the carer and the person with dementia. Supporting the carer requires not just direct services and supports but a whole-society response to reduce stigma and promote the inclusion of people with dementia and their carers in the community.

Identification of older carers and carers of older people can be an issue as carers may not see themselves in that role but as parent, spouse, partner etc..It is incumbent upon us all to support our older carers who want to continue in their role, for as long as possible. This can be done by assessing and monitoring their needs and enabling them to meaningfully engage with the support available in each of their own jurisdictions.



1	Northern Carers Social Group - Isle of Man Government	Page 22
2	Extra Care Housing - Guernsey Government	Pages 23-24
3	Dementia Elevator - Irish Government	Pages 25-26

1 Northern Carers Social Group - Isle of Man Government

Overview:

A social support group for carers in the North of the Island, facilitated and supported by Community Older People's Social Work Team as part of the work of the Adult Social Care Division of the Department of Health and Social Care.

How does it work:

The Northern Carers Social Group has been running for around 2 years for people who live in the North of the Island. The initial intention was to provide a social gathering opportunity for carers to meet with professionals in order to seek advice and guidance.

The venues range from restaurants (evening meals, lunches) train/tram trip, Wildlife Park, bowling, and the latest was a visit to the Community Farm – places that people may not have been due to time being spent with their loved ones. These activities give carers time to relax in a friendly environment away from their caring role which can be very demanding and overwhelming at times.

The group support each other and have formed friendships outside which has helped them to deal with carer stresses. It is good to share personal experiences and for people to know that they are not alone. Professionals from social work and mental health are on hand to signpost for services.

The group has grown over time and we now have around 50 people on the mailing list. It works on an open invitation which is coordinated via the social work team and people pay for themselves.

What has been the impact:

The group is hugely beneficial for carers who attend, giving them time to reflect, relax and gain support through the challenging periods in their lives.

Carers are enabled to access support from the Department of Health and Social Care's Older People's Resource Centres in that the cared for can spend time in day and residential centres for a small charge in order to enable the carer to participate with confidence.

From a survey of Carers Group members undertaken in 2016: What are the benefits of attending a carers group for you?

Supporting each other with those who understand and also from learning ideas and ways how others cope with various situations

Having a laugh and being out without being 'the carer'

Meeting with other carers that you can have a chin wag with from one month to another

Seeing others that are going through the same thing as you are and how they are coping

Sharing experiences – you know you're not 'the only one'



2 Extra Care Housing - Guernsey Government

Overview:

In 2011 the States of Guernsey agreed to develop two sites which were previously States-owned care homes into new forms of supported accommodation for people who needed on-site care and support. The first phase of the sites was completed in 2014 and these have since been expanded with a second phase of developments. The two sites include 161 flats.

On-site care and support is provided by a team which is managed through the States' Health & Social Care Service. Adults (18+) who need an average of at least four hours care and support a week can apply for accommodation on these sites which include a mix of rental and partial ownership agreements and are managed by the Guernsey Housing Association.

How it Works:

In the past care services have been structured in such a way that if somebody needed on-site residential care or support their needs have been met through care home provision. In some cases this meant that families who

wanted to live together and support each other were housed on different sites. Twenty families are currently supported in the schemes.

Through provision of one and two bedroom apartments, our extra-care housing provision improves opportunities for family members (aged 18+) who want to live together. Joint working between specialist teams means that the housing can be used to support people with mental health conditions, learning disabilities, palliative care needs and physical disabilities as well as older adults.

Families might include one person with support needs, or more than one person. This might include, for example, families including older adults and younger adults with learning disabilities; and older couples and siblings who wish to live together.



What is the impact:

Living with on-site support means that carers can continue to support their family members, which can reduce the amount of staff input needed, but with less risk or pressure if a carer is unwell, as staff can step in.

Both of the extra-care developments have café areas and community facilities which are open to wider community groups that come into the developments to use the space. This can help to reduce the social isolation of carers living on the sites, both by offering opportunities to meet other carers within the developments and by providing a convenient way to participate in community groups running activities such as dance classes or U3A courses.

Alongside supporting some families to stay together living in the scheme, the extra-care housing developments also offer short-break services to families living in the community, and host day centre services.

"It is fantastic being here, lovely. I never feel alone. My daughter has improved since moving here, she has become more independent, our social life has improved. It has done my daughter good, and improved all of our lives. I feel my husband is more confident." Resident

"If I hadn't come here I would have gone out of my mind. The staff are friendly, it has been a good move, someone is always around. It's a relief having a call system to alert the staff and we are happy with the response when we use it." Resident

"Being here has eased the care of my daughter during the day. It was a good move, it gives us peace of mind having [professional] carers around. We are still independent in our home." Resident

**3 Dementia Elevator - Irish Government****Overview:**

Dementia Elevator is a national dementia education and empowerment programme developed by Dublin City University and the Health Service Executive to help individuals, communities and health systems engage with and support people with dementia. The main motivation behind Elevator is to ensure that there are people in communities with the right skills to make staying at home a more obvious choice than is currently the case for people with dementia.

The programme seeks to help those who work with people with dementia to increase their knowledge about the condition. The project is tailored towards anyone who engages with people with dementia, including health and social care professionals, service leaders, family carers, and the wider general public. By offering modules that help the wider community to understand the condition, the project hopes to successfully challenge the way society thinks about dementia. Many of these modules are available free of charge in locations across the country. They can also be found online at: www.understandtogether.ie/training-resources/dementia-awareness-training.

As part of this work, the project has developed an online skills-based module for carers of people with dementia called 'Dementia Coping Skills for Families and Carers'.

This comprehensive programme aims to provide carers with a range of skills to enable them to support the person with dementia in their care, and to help them live well in their homes for longer. This is provided online, free of charge, at: www.elevator-carers-coping-skills.com

How does it work:

Focusing on ability rather than disability, Dementia Elevator takes a person-centred approach to dementia care. The 'Dementia Coping Skills for Families and Carers' programme was developed in close consultation with family carers of people with dementia and health care practitioners. Participants are taught to recognise the emotions, goals and coping strategies of the person with dementia, while learning about the importance of self-care.

The programme content is divided into five chapters:

1. Focusing on the person with dementia;
2. The importance of self-care;
3. Maintaining relationships between carer and the person with dementia;
4. Understanding and exploring emotions of a person with dementia;
5. Supporting the person with everyday activities.

The training aims to be interactive and engaging. Features include interviews with people with dementia, family carers and professionals, a range of video examples demonstrating the skills in everyday situations, a personal narrator and use of characters, a downloadable personal reflection journal, and a resource pack for group delivery.

Within each chapter, there is a range of additional resources, including websites, factsheets, YouTube videos, a blog by a person with dementia, information about brain health, and tips on memory retention. Each chapter also has a transcript, for the benefit of carers who may be hard of hearing.

The programme has been widely disseminated to organisations related to family care, dementia and ageing, such as the Health Service Executive, Alzheimer Society of Ireland, Alzheimer Cafés and Family Carers Ireland.



What has been the impact:

Feedback from a pilot face to face delivery of the programme was positive. The participants seemed to be challenged in their existing view of dementia and developed an understanding of the importance of the identity of the person with dementia. Participants were able to identify helpful skills in managing self-care, for example accepting that it's okay to ask others for help. The programme is structured in such a way that carers of a person with early stage dementia need only access content relating to dementia in the early stages, and can choose to look at content relating to mid and later stages when they require it.

It is planned that the programme will be delivered in a group setting in local communities throughout Ireland.

“
It touched on real life situations....This is a professional view on how to deal with these situations

The techniques are brilliant

It makes it very clear that (my father) is as much of a person as he always was.
”



Caring skills, self-care and technology enabled care

Pages 28-33

The evolution of technology has revolutionised social and health-care and changed the landscape of interaction and dependency between service user and practioner. Officials from this work sector have seen first-hand the effect that this has had on both carers and cared-for persons, as it is increasingly used in the provision of additional support for both.

Assistive technology has been shown to help promote independence and improve the quality of life for the cared-for person. In particular, it has been used to help with parts of their lives that can vary in difficulty, from basic household tasks to shopping. This can allow the cared-for person to remain at home, living independently, for longer than previously expected.

The consequence of this is that the extent to which the cared-for person depends on their the carer is eased. This enables the carer to have more flexibility, and a life alongside caring, whilst the cared-for person retains the same level of care that they require.

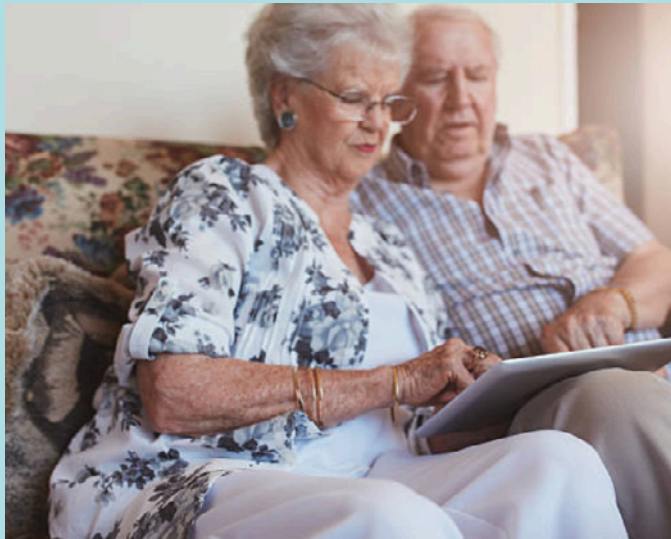
A short break can also improve the capacity and resilience of a carer. By providing the carer with a period of rest will enable them to feel more refreshed when returning to their caring role. Carers report better wellbeing outcomes themselves when they have short breaks from caring.

Similarly, skills capacity-building is a process by which an individual can obtain, improve, and retain the skills and knowledge that they may require as a carer. It can, however, also refer to the development of existing skills that an individual has, from both their personal and professional life, to better use these to support themselves in their caring role.

Site visits and policy sharing between the BIC administrations show that training courses are not simply about keeping up to date with their

knowledge, skills and understanding. They can help to develop an individual's confidence in undertaking their caring role, by helping them achieve a skill that allows them to be resilient and motivated. Contemporary support from other carers, alongside that of the trainer, will also make a carer feel less isolated and more supported in the long term, even though these individuals are not friends or family members.

The examples in this section demonstrate the use of training and technology to enhance the skills of carers and to continue to develop new and relevant ways of supporting them.



1	St Johns Ambulance - Jersey Government	Pages 28-29
2	Informal Caregivers - Northern Ireland	Pages 30-31
3	South Tipperary Memory Technology Library - Irish Government	Pages 32-33

1 St John Ambulance

Overview:
St John Ambulance Jersey runs three different programmes for carers in Jersey. The Carer's Support Programme is the charity's main service however, they also run a supplementary programme called First Aid for Carers and, more recently, have launched the Carer's Support Group.

How does it work:
The St John Ambulance Carers Support Programme was launched just over ten years ago. The programme is for anyone who cares for a friend or family member in an unpaid capacity, whether a short time every week or as a full-time carer. It is not available for anyone who is a professional carer or anyone who receives payment for caring. The programme is led by a registered nurse and trainer and they run three or four sessions each year, with a maximum of 14 carers.

The Carer's Support Programme is made up of four sessions, which cover a range of aspects to help equip the carer with knowledge on how to look after themselves as well as the cared for person. Most sessions are run by the Care Programme leader, although visiting speakers are invited from various government organisations and services.

As well as the Carers Support Programme they have also introduced a course called First Aid for Carers, which is a one-off session for five hours. Carers who have attended the initial programme have an introduction to first aid, although First Aid for Carers covers a wider range of first aid topics.

It is also of benefit to volunteers who work with other charities who look after carers within their charity.



The recently launched Carers' Support Group is the initiative of the new Care Programme leader, designed to offer on-going support to carers who attend the initial programme. The format includes visiting speakers and activities – session two included Zumba and talking a little about the advantages of music and dance both on the wellbeing of carers and those they care for

Sessions included in the programme:

A Carer's role
- Looking after yourself as a carer
- Principles of care around the individual's daily needs
- Discussion on a Carer's Assessment
Looking after your back
- Advice on daily back care, prevention of injury, relevant to caring at home
- Practice in handling techniques in a safe environment
Stress management
- Understand stress
- Relaxation techniques
Benefits
- Guest speakers from advisors who share information on benefits available for carers
Safety in the home
- Guest speaker from Jersey's Fire Service
First aid
- What to do if an accident happens in the home
- Prevention of trips and falls

What has been the impact?
Most of the people who have attended the programme have had little or no support from elsewhere and without St John Ambulance they would not have had any advice on moving and handling, looking after themselves and for their cared for person. Some carers were not aware of benefits they are entitled to and find it hard to know who to talk to.

Carers who have attended the programme have said that the tips they have learnt through attending the programme have been a 'huge help' at home and have made 'such a difference'.

At the beginning of the programme all attendees complete a short questionnaire which gives an indication to the Care programme Leader as to each attendee's prior knowledge in each area. They then have the opportunity to complete this form again at the end of the fourth session to show how they have gained knowledge together with any additional feedback.

Quotes from carers:

"I found the first aid course offered to carers most useful... it was very reassuring to have the basic, essential knowledge gained during the course. It gave a good grounding for going on to take a more advanced course if one's situation demanded it. I would recommend it."

"As an informal carer, first aid is an invaluable skill to have to hand should accidents happen. The training provided by the trainers through the Carers Course was very well delivered and leaves you with the comfort that you can deal with the issues that come up in day to day life, as well as should something more serious occur."

"Very helpful, informative, instructive, easily understood, practical, just excellent."

Quotes from trainers who run the service:

"The programme is rewarding and I feel privileged to be able to help individuals who find themselves caring for another, to offer practical help and support which in turn should make the role of the carer easier."



2 Informal Caregivers - Northern Ireland Executive

Overview:

Provision of short breaks and training for Informal Caregivers of people living with a dementia are important issues of concern. Informal Caregivers play critical roles in providing support to people living with a dementia to enable them to remain living in their own home/ community.

Their role is often a complex and challenging task and they experience greater strain and distress which sometimes can be linked to a wide range of outcomes including physical ill health, relationship changes and restrictions to social activity and isolation.

Attending customised training ensures that carers are better equipped with the knowledge, skills and understanding to enable them to continue to care for a person living with a dementia. This helps them develop confidence and resilience in undertaking their caring role and they receive peer and trainer support. The short breaks also provide a break from caring in order that carers can rest and then return to providing care to the person they care for more refreshed. Carers report better well-being outcomes themselves when they have short breaks from caring.

How does it work?

The provision of the training ensures that the informal Caregivers are made aware of, and can access, relevant services for their loved ones as they travel through their journey of dementia. This particular training was delivered as part of a larger pilot scheme (Dementia Signature Project) which was funded as part of the Northern Ireland Executive's Delivering Social Change Programme with associated learning to be integrated into further training commissioned by the Health and Social Care Trusts.

The training was delivered by 2 service providers across the region over a 4-6 week period. The training was delivered in the family's own home or they could avail of the training in an external environment where they could meet other carers in a similar position, thus gaining peer support as well as informative training. There were 6 modules in the course, covering a variety of topics relating to providing care and support,

from legal and financial issues through to managing behaviour and communication. This gave the carer a comprehensive level of knowledge and skills to enable them to fulfil their vital role in the best way possible.

There were a total of 5 pilot non institutional short break services being tested across the region with the aim of providing support to carers in a way that works best for them and the person they care for. These included enhanced befriending, emergency support, extended domiciliary care, enhanced day opportunities and short breaks away. These services offered the opportunity for carers to have a break to focus on themselves, secure in the knowledge their loved one was being supported by someone who knew their needs and was appropriately trained to deliver the support. The extended domiciliary service was extended across the region and allowed carers a 2-4 day break away whilst the person with a dementia is cared for in their own home.

The short break provision allowed people to be cared for in their own homes and reduced the disruption and anxiety care home admission can cause for all involved. They also ensured continuity of care in the person's own home and carers report that on their return the person living with a dementia had experienced little disturbance to their routine and so their absence had minimal impact on the persons care.



Individual Training for Caregiver

What has been the impact:

Data – Since May 2016 a total of 1,278 informal carers have been trained and a total of 166 Carers/ People living with Dementia availed of the Short Break pilots.

Outcomes – Evaluation of the overall Dementia Project is ongoing and will be completed by March 2018.

Sustainability – As this was a pilot scheme under the auspice of the Dementia Signature Project (Dementia Together NI) funded under the NI Executive Delivering Social Change Programme the outcomes of the findings of the final evaluation will be included in the final sustainability plan for the entire project due to be finalised by March 2018. However, within the plan it is proposed that a communications exercise to communicate lessons learnt and benefits of the scheme to both service users and stakeholders, with an intent to facilitate change in the mainstream provision, will be undertaken by the Health and Social Care Board.

Research – Extensive Scoping Papers were prepared for both services in the Spring of 2015 and these were based on interviews with Carers and People living with Dementia as well as incorporating desktop research.

Quotes from Dementia Carers who attended Informal Caregivers training

“Very good course, it addressed all the major issues that I was concerned about and things I hadn't thought of. I found it really helpful knowing how to support my Mum, communicate with her better and make her feel more included. All the information was very illuminating and very helpful especially the little things we talked about, it will make a big difference to my life.”

“Very compassionate and empathic. Small group made it easier to share and discuss. Lots of information given, helpful to be able to read up on the session at home with the workbooks. I feel more confident in my role as a carer and the care I give. Also knowing other things I wasn't aware of or thought about.”

Quotes from Carers who received short breaks

“Not only did Mum benefit from it but me, as a carer, found it to be priceless.”

“When I came home Mum was just as she would have been had I not been away! I really noticed the difference (for the better) from occasions where I had to place mum in respite.”

“This service allowed us to take a family holiday. It was wonderful to get a complete break. Completely happy that our father was happy and being looked after well.”



Group Training Course for Informal Caregivers

3 South Tipperary Memory Technology Library - Irish Government

Overview:

South Tipperary Memory Technology Library (MTL) is a dementia specific assistive technology information service that offers high quality individualized support to people with dementia, their family carers and health care professionals.

The MTL is the first of its kind in Ireland, is innovative, accessible to all who want to visit and enhanced by a comprehensive website.

Assistive Technology is an underused resource for people with dementia, promoting independence and quality of life. Assistive technology has helped people with dementia with aspects of their daily lives that are both simple and complex. It can contribute to cost effectiveness by supporting people with dementia to live at home for longer than might otherwise be possible.

The objectives of the service are:

- To raise awareness of the potential offered by assistive technologies;
- To give up to date/ real user feedback /practical information on the benefits and limitations of specific assistive technologies;
- To offer a user friendly, useful (problem solving) service to people with dementia, their families and health care professionals.

Based on the success of the South Tipperary Memory Technology Library and a similar Resource Room in Clonskeagh in Dublin, the Health Service Executive is rolling out a national network of Memory Technology Resource Rooms, with one in each Community Healthcare Organisation. Funding for the expansion of the Resource Room network has been secured from the Dormant Accounts Scheme.

How does it work:

The South Tipperary Memory Technology Library (MTL) was established as a pilot project with philanthropic funding in response to the needs identified by people with dementia and their carers. It is accessible through self-referral and visitors are offered an hour's

appointment with an occupational therapist to discuss the issues they are hoping assistive technology (ATs) will address. The occupational therapist demonstrates suitable products, and is able to offer practical strategies, behavioural and occupational advice and local sign posting to other services where needed.

People with dementia living in South Tipperary have the option to borrow certain products for up to a month, allowing people to take instruments home and to use them in a familiar environment. Evaluation and detailed feedback forms are completed by all who visit the MTL and those who borrow ATs.

The ATs enable people with dementia to retain a level of independence. For carers, ATs can inform them if medication isn't taken or trigger sensors in an emergency.

Apart from ATs, the MTL also has a range of useful resources for dementia care such as books and activity resources that can be useful for maintaining skills and promoting wellbeing.

The MTL has developed and facilitates a Memory Rehabilitation Group for newly diagnosed people and their carers. This was in response to a significant gap in service for people in the early stages of dementia.

The MTL regularly develops and carries out relevant research. The aim of the research is to assess client experiences with items of assistive technology, i.e. standalone ATs; telecare technologies and GPS tracking devices. South Tipperary will become the hub for disseminating research with the new Memory Technology Resource Rooms.

Impact of the practice:

South Tipperary MTL was piloted between June 2014 and April 2015. Over 250 people visited the MTL during this phase, with 200 people completing visitor questionnaires. 40.5% of visitors were HSE staff, 20% were family carers, and 6.5% were people with dementia. The questionnaires found 97% rated the MTL as "very useful", and 86% found potentially useful technologies during their visit. People with dementia spoke about how ATs maintained their independence, while family carers appreciated the value of being able to loan items. Healthcare professionals commended the range of devices available.



Demonstrating fire alarm



Quotes about a piece of assistive technology loaned

"If she's confused she knows to look at the clock. Now I think she is more settled in herself, a lot calmer. She gets up, but now she goes back to bed if its dark, if she gets her sleep it has a positive effect for the rest of the day. She is not so disorientated."
Family carer

"Learned about things I can put in place for my dad that I never knew were available."
Family carer

"So beneficial it helped me with the days of the week, it made a big difference, I remember then what to do each day."
Person with Dementia

"I was not aware of the variety of technologies and items available, good to see how elaborate and simple products can benefit and enhance people's lives."
Volunteer organisation worker



Demonstrating a bed pad

Bereaved Carers

Pages 35-37



Dealing with bereavement as a carer can be extremely difficult, and it is important to recognise that the impact of being a carer does not end simply with the passing of the cared-for person. To better inform their work in this area, officials from the Social Inclusion work sector met in February 2017 with an all-Ireland organisation which gave an insight into their work providing online and face-to-face peer support services for bereaved parents.

Though a carer could have been looking after someone who has been ill for some period, it does not necessarily mean that coping with their bereavement will be any easier. The length of time and the intensity of the caring situation is irrelevant – despite being ‘prepared’ for this eventuality, the death of a loved one can be a great shock, as the cared-for person may have been a parent, or a young child.

The act of caring can often be intense. A carer may find that their life is heavily synchronised with the cared-for person, and that they have found a purpose and identity in their caring role. It is also possible that they have made sacrifices in providing care to their loved one, such as friendship or employment. Another possibility is that they will be financially burdened by the death of a loved one. This bereavement can therefore leave them isolated, and without a sense of direction.

Often people will experience grief in its differing forms and for varying periods after their loved one’s passing. This means that support given following such an event cannot have a timeframe; the carer must be supported for the duration of their adjustment.

By supporting bereaved carers, it is possible to help them to readjust and carry on with their own lives. It is important that individuals are supported in the caring void that can exist following the conclusion of a caring role. This can sometimes be through volunteering or helping other carers, attending peer support groups and social occasions or by having conversations with others who are experiencing or have experienced the same event.

The examples in this section demonstrate the ways in which the BIC administrations have supported our carers who have suffered a bereavement, and how we can continue to support them after their caring role has ended.

1	Carers Support Group - Guernsey Government	Pages 35-36
2	Carer’s Allowance for Former Carers - Irish Government	Page 37

1 The Carers Support Group - Guernsey Government

Overview:

The Carers Support Group, which was established by the Older Adult Community Mental Health Team in 2015 and taken on by the Guernsey Alzheimer’s Association in 2016, provides continuous support for carers from the start of their caring journey until after their caring role has ended.

How does it work:

The group meets weekly as part of a broader programme of activities run by the Guernsey Alzheimer’s Association, which includes other support for carers such as a sitting service and a grant scheme as well as social opportunities to spend time with carers and the people with dementia that they care for such as a free monthly lunch, social afternoons and Singing Down Memory Lane.

The social network and support developed with other carers from participating both in the carers group and in the other social activities organized by the Association can be an important source of support at different points in the caring journey.

At its meetings carers can bring the relative or friend that they support with them to participate in a parallel session for people with dementia whilst they take time to meet with other carers.

Sessions provide carers with time to get to know others in similar circumstances to their own, support each other and receive information from visiting speakers who provide advice on relevant topics and raise awareness of other support services that are available locally. Themes covered include managing difficult behaviors, managing stress, managing legal issues and so on.

Joint working between the Older Adult Community Mental Health Team at the Memory Clinic and the Guernsey Alzheimer’s Association helps to ensure that carers are identified early in their caring journey and that they are offered support at an early stage. Contact is usually made shortly after diagnosis. The carers group can then provide a supportive community from the beginning of this journey through until after their caring role has come to an end.

The group particularly recognises the importance of the carer’s role in supporting people with dementia in the community and recognises that undertaking this role can provide its own challenges.

The Carers Support Group continues to support people whose caring responsibilities have ended (including by bereavement), in recognition of the fact that maintaining the social support from the group is important for people who are bereaved. Adapting to the life changes that this can entail can take some time.

There is no time limit on attendance; people can continue to attend as long as they wish to. People whose care responsibilities have come to an end can often offer support and advice to current carers and are valued members of the Group. Including carers who are at different stages of the caring journey can help to enhance the quality of peer-support that the group can offer.

Carers who have stayed with the group having been bereaved for some time may also be in a position to help to support recently bereaved carers with the emotional and practical aspects of their loss, as well as transitioning into life after caring. Some have also found that talking through topics with visiting speakers helps them to understand what has happened in the lead up to the loss of their loved one.



What has been the impact:

The group supports carers throughout their caring journeys. As the group has become better known, more carers are turning to the Association for advice and support.



"They encouraged me to come after my husband had passed away. I can't speak highly enough of the group. The volunteers are amazing. The understanding and friendship is great. It is nice to know I'm not alone."

Participating carer

"Coming here has changed my life because I was on my own before"

Participating carer

"Guernsey Alzheimer's Association carers support group is invaluable, the weekly talks are very informative and the sitting service provided is excellent"

Participating carer

"carers still need that support. We hope to see more carers come in future, some people are reluctant to come but once they are here they immediately see the value of it."

Guernsey Alzheimer's Association representative



2 Carer's Allowance for Former Carers - Irish Government

Overview:

Former carers, who have ceased their caring role as a result of bereavement or the admission of the care recipient to permanent residential care, have been identified as being particularly vulnerable. Caring can isolate carers from friends, family and local community and the world of work.

The Department of Employment Affairs and Social Protection engages regularly with carer representative groups through an annual Pre-Budget Forum, an Annual Carers Forum and through meetings of the Community and Voluntary Pillar. These fora present an opportunity for carers and their representative groups to discuss issues directly with policy makers.

The financial uncertainty facing former carers and proposals to enhance social protection measures for this cohort featured at these fora and the Department of Employment and Social Protection undertook to explore options that would address this..

How does it work:

When a carer's full-time role comes to an end, either as a result of bereavement or the admission of the care recipient to a residential care setting, Carer's Allowance continues to be paid for a period of 12 weeks.

The continuation of the payment provides a period of financial certainty during which a former carer can grieve, adjust to a life post care, and make plans for the future.

The Department of Employment Affairs and Social Protection provides other supports to former carers of working age, who are encouraged to discuss, on a voluntary basis, their future employment or training options by making an appointment with a case officer through the local Intreo Service.

An engagement with the Intreo service after 12 weeks (or earlier if the carer feels ready to engage) ensures an appropriate early intervention for those of working age. Existing evidence indicates that prolonged absence from the workplace is associated with poor employment outcomes unless there are appropriate interventions.

The measure is consistent with the goals 2 and 4 of the National Carers' Strategy, which are to support carers to manage their physical, mental and emotional health and well-being (Goal 2), and empower carers to participate as fully as possible in economic and social life (Goal 4).

What is its impact:

Research indicates a post care trajectory involving a caring void in the period immediately following the ending of the full time role, a period of adjustment when the role is being "closed down" and a period when the former carer begins to construct a life post caring.

There has been positive feedback from sectoral representative groups and former carers.

