



# LIVING WELL IN THE SCOTTISH BORDERS 2019-2022

*Draft Plan for Carers*



# **Carers – Living Well in the Scottish Borders**

## **A plan for carers 2019 -2022**

### **Foreword**

Carers – Living Well is a plan for unpaid carers in the Scottish Borders. In Scottish Borders we recognise the significant and vital contribution that carers make in supporting those they care for.

The way health and social care is delivered locally is changing and one of our key priorities is that carers are supported to be able to continue to care, if they wish to do so, with the best possible health and well-being.

To this end, we are focussed on working towards listening, supporting, informing and empowering carers throughout the Scottish Borders.

To ensure we maintain this focus, the Scottish Borders Health and Social Care Partnership has identified carers as one of their key priorities. By doing this the future direction locally will reflect what is important to carers and provide them with an opportunity to shape and influence the delivery of services both for them and those they care for.

Carers – Living Well sets out the approach and the action plan by which the Health and Social Care Partnership will deliver on our visions and outcomes for carers for 2019 -2022

### **Where do we want to be?**

**Our Vision**– is a Scottish Borders which recognises and listens to carers so that they feel valued and supported, can feel as well as possible and able to have access to a life outside the caring role, if they wish to do so.

### **Why do carers matter?**

There are many unpaid carers throughout the UK and 1 in 10 of us will become a carer at some point.

According to the 2011 Census:

- Caring often impacts negatively on health and wellbeing. Caring for a loved one who is ill can take a serious toll on the carers' mental and physical health, their personal relationships and family finances, the educational attainment of young carers, and we know that being a carer is a key factor which can lead to social isolation.
- Carers save the Government money. Many carers support people who would otherwise need statutory services, therefore saving the NHS and Local Authorities money. The economic value of the contribution made by carers in the UK is £119b per year.

## Why do we need to support carers?

According to recent research by Carers UK (2014):

- 6 in 10 carers have been pushed to breaking point
- 25% of those who had reached breaking point required medical treatment as a result
- 46% of carers said they had fallen ill but just had to continue caring
- 1 in 9 said the person they cared for had to be rushed into hospital, emergency care or that social services had to step in to look after them while the carer recovered
- 1 in 5 were forced to give up their jobs because they were in crises
- There will be more carers in the future.
- The number of carers is set to increase as people are living longer with disabilities and long term health conditions. The pressure on families to care in their own homes, particularly for spouses and partners, is growing significantly and is predicted to double in the next 30 years

1 <http://www.carers.org/key-facts-about-carers>

2 <http://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report Version 14.0 7>

## Introduction

### Who is a carer

In Scottish Borders, we follow the definition of a carer as outlined in the Carers (Scotland) Act 2016 which is as follows: “carer” means an individual who provides or intends to provide care for another individual (the “cared-for person”). A carer is anyone who, unpaid, looks after a friend or family member who can't cope alone due to illness, disability, a mental health problem or an addiction.

A young carer is a child or young person who has a significant role in looking after someone in their family. They may have practical caring responsibilities or be emotionally affected by a family member's care needs.

The Act defines a Young Carer as a person who is (a) under 18 years old, or (b) has attained the age of 18 years while a pupil at a school, and has since attaining that age remained a pupil at that or another school. The Act defines an Adult Carer as a person who is at least 18 years old but is not a Young Carer.

- A carer could be a spouse, partner, parent, sibling, child (usually referred to as a ‘young carer’), friend or any other relation. Anybody from any background and of any age can be a carer and each carer's experience is unique to their own circumstances. Carers are often hidden and do not recognise themselves as carers but first and foremost as a spouse, partner, parent, friend etc.

Just as the reasons why someone becomes a carer vary greatly, the variety of tasks that a carer fulfils is diverse. They can include any of the following: practical tasks such as cooking, cleaning, washing

up, ironing, paying bills, financial management and engaging appropriate services; personal care such as bathing, dressing, lifting, administering medication and collecting prescriptions; and emotional support such as listening, advocacy, problem solving, motivating and companionship.

Our definition of a carer does not include people who are employed to provide care e.g. care workers, home care staff, district nurses, foster carers and people who work in an unpaid capacity for a voluntary organisation.

## **What is ‘Carers – Living Well in the Scottish Borders’?:**

‘Carers - Living Well in the Scottish Borders’ is a plan for unpaid carers living in the Scottish Borders.

- It focusses on achieving positive outcomes for carers
- It sets out a plan for the involvement and engagement of carers
- It aims to improve the lives of carers in the Scottish Borders
- It sets out where we want to be in the future
- It recognises carers as experts and partners in care

## **Why do we need ‘Carers – Living Well in the Scottish Borders’?**

- Unpaid carers are a vital part of health and social care provision in the Scottish Borders. Without them the health and social care system would collapse, so we need to ensure that there is robust support in place for them
- The interim carers strategy for carers comes to an end in 2019
- It is a requirement of the Carers (Scotland) Act 2016 that a plan for carers is developed between NHS Borders, Scottish Borders Council and carers.

## **Who is the plan for?**

- Carers living and caring in the local authority area
- Living in the local authority and caring for people elsewhere, and
- Not living in the local authority but caring for a person or people who live in the local authority area

## **Impact of caring**

Becoming a carer can be rewarding and have a positive impact on relationships, however it can also bring challenges such as:

- “Me Time” and time to switch off from responsibility
- Strain on relationships and risk of relationship breakdown
- Juggling caring responsibilities with other responsibilities such as work and dependants
- Feelings of social isolation
- Poor physical and mental health
- Reduced financial circumstances

‘When I became a carer it was literally a bolt from the blue. I had never thought about being a carer or what that might mean. It started off as a normal morning – my husband had complained of a bit of a headache the night before but when he woke up he just wasn’t right. He was confused, wasn’t speaking properly and said he felt numb down one side. I phoned 999 right away and before we knew it he was on a stroke ward and I had become his main carer. Things were never the same after that. After several weeks in hospital Roy came home and although he had made some improvements, he needed a lot of help with washing, dressing and getting about. I was afraid to leave him even for a short time. Something like this knocks your confidence. We’ve managed but it’s not been easy. We’ve both had to give up work and I am tired all of the time. This isn’t how we thought retirement would look and it’s been tough having Roy under my feet all of the time. We’ve had to find a way through though and now we’ve got some support things are better. You just have to get used to things being different. I miss our old life but we are adjusting and making the best of it. We are positive people but sometimes you can’t help wanting the things you used to have. We don’t see as much of friends as we used to which is hard for both of us but gradually with the support of the carers centre we are getting things sorted out, and that’s really an important message that you don’t have to do it all by yourself. There is help out there and don’t be afraid of taking it. It makes a difference a really big difference and I feel I am coping now where I wasn’t before. Things don’t seem as bleak and we’re back on track.’

The Borders Health Needs Assessment provides us with robust data on the impact of caring on unpaid carers in our area. 135 responses were received from the Care Experience Survey:

- 55.6% reported sleep deprivation
- 82% reported they neglected their own health
- 52.8% reported a negative impact on their physical health
- 63% were concerned about lack of exercise
- 14.9% were concerned about alcohol intake
- 78.7% reported poor mental health
- 44.5% reported financial concerns

## **Background to the plan**

The Carers (Scotland) Act 2016 gives brings new rights to carers and is intended to ensure that carers are better supported so that they can stay healthy and have a life alongside caring.

‘Changing Health and Social Care: the Scottish Borders Health and Social Care Strategic Plan for 2018-21’ places carer support as one of their key priorities.

An interim strategy Caring Together 2018-19 has helped to inform this plan. Since April 2018.) there has been a 33% increase in the number of carers taking up the offer of a Carers Support Plan with reported improvement in all five key areas of the Support Plan.

## **The demand for support**

In April 2018 the “Health Needs Assessment of Carers in the Scottish Borders 2018” was published. This piece of research is the first of its kind for the Borders and was the result of a joint venture between Public Health, Local Authority and third Sector and of course was informed by carers.

The research provides us with a useful source of data as well as providing us with clear evidence of the needs of carers in relation to health and well-being. The recommendations from the HNA are embedded in this plan.<sup>1</sup>

The Scottish Health Survey (SHeS; most recently published 2016<sup>2</sup>) also provides us with some useful national data across Scotland and is useful for identifying trends.

For adults aged 16 years or older, for 2015/16 SHeS tells us that:

- 15% provide regular care
- 65% provide care up to 19 hours per week
- 15% provide more than 50 hours of care per week
- 6% said if differs from week to week

This is an increase in Scotland's 2011 Census<sup>3</sup> figures as below and evidences a growing trend.

- 11% provide regular care
- 6.1% provide more than 19 hours of care per week
- 3.9% provided over 35 hours of care per week

Another useful survey for demographic data is the Health and Care Experience Survey 2015/16<sup>4</sup>, which is a national survey broken down into local areas.

In Scottish Borders 2970 people responded to the survey. The survey asks the question: "Do you look after, or give any regular help or support to family members, friends, neighbours or others because of either long term physical, mental ill-health, disability or problems related to old age?"

11.8% of respondents identified themselves as carers.

Of this:

58% were female  
48% were male

Borders Health Need Assessment<sup>5</sup> states, in conclusion, that the figure 11.8% "is perhaps the most reliable estimate for the Borders, given that the data is local and very recently collected. If we extrapolate this up from the survey this would equate **to 13,455 carers living in Borders** (based on population estimate of 114,030m people living in Borders currently)<sup>6</sup>

<sup>1</sup> Health Needs Assessment of Carers in the Scottish Borders

<sup>2</sup> Scottish Health Survey 2016: Volume 2 <http://www.gov.scot/Publications/2017/10/4796/downloads>

<sup>3</sup> Scotland's Census Shaping Our Future 2011 <http://www.scotlandcensus.gov.uk/census-results>

<sup>4</sup> Health and Care Experience Survey 2015/16 <http://www.hace15.quality-health.co.uk/reports/health-and-social-care-partnership-reports/2458-scottish-borders-pdf/file>

<sup>5</sup> Borders Health Needs Assessment pg 10

<sup>6</sup> National Records of Scotland Figures for 2015

## **Involvement and engagement with carers in the Scottish Borders**

Services for carers and the people they care for should be joined up, delivered locally, tailored to individual need, and person centred to meet individual outcomes. They must be developed in partnership with people and communities.

In order to achieve this carers must be involved in all aspects of planning health and social care in the Scottish Borders. Carers need to have a strong voice and strong representation to ensure that decision makers fully understand the wide ranging impact of caring on physical and mental well-being, social interactions, finances and future planning.

### **How do we do this?**

Carers Advisory Board – the Borders Carers Centre facilitates a forum for carers to ensure that carers have a strong voice locally and are able to feed into local and national development. The group is for and led by carers

Parent Carer Working Group – Borders Care Voice and Borders Carers Centre facilitate a forum for Parent Carers to ensure that they have a strong voice locally, can address issues and influence service developments and delivery. The group is for and led by carers

Health and Social Care Partnership – a carers representative sits on the Health and Social Care Board to represent the views of carers and raise issues which impact on them

Carer Support Groups – these are run throughout the area on a monthly basis and provide peer support as well as an opportunity to share information, inform and consult

Carers Week – the week is celebrated with an open event for all carers in the Scottish Borders. As well as an opportunity to celebrate and thank carers for everything they do, it also provides an opportunity for carers to learn about local and national developments and have their say. Feedback from this event is used to inform future planning

E-bulletin – the Carers Centre sends out a monthly e-bulletin and annual newpage to carers who have signed up to ensure that they are well-informed about local and national activity and developments

Survey – we share on a regular basis surveys and consultations that are relevant to carers both electronically and in hard copy

Media – we use local media, SBC communications

### **What carers have told us matters to them**

To ensure that we are listening to carers and to fully understand what matters to them, as part of the development of this document, the local Health Needs Assessment asked carers to complete a questionnaire; a consultation questionnaire invited people to contribute to the 2018-19 interim strategy 'Caring Together'; and The Borders Carers Service also carried out an evaluation and an event was held during National Carers Week.

Carers told us that the following was important to them:

- To be recognised and supported
- To enjoy a life outside caring
- To have access to short breaks
- To not be financially disadvantaged
- To be mentally and physically as well as they can be
- To be treated with dignity
- To be involved in shaping policy and services
- Support and training for to help them in their role
- Support at times of change, including preparation for adulthood and end of life
- Emergency and future planning
- Housing support, including adaptations and equipment
- Information and advice, including on benefits and financial issues
- Peer and community support
- Support to maintain and access work and training

This information has been used to identify 7 key themes which are at the heart of the plan

## **Key Themes**

- Carer identification and recognition
- Information, advice and communication
- Carers Rights
- Support
- Health and well-being
- Breaks from Caring
- Access to Services

## **How to achieve this?**

### **What we do now?**

The Borders Carers Centre is funded by the Health and Social Care Partnership to provide a “one stop shop” for unpaid carers throughout the Scottish Borders. The Centre provides information, advice, advocacy and emotional support and also has the responsibility for carrying out Carers Support Plans on behalf of Scottish Borders Council.

The Carers Centres aims to respond to referrals within one week. Carers are provided with an introductory letter which includes information about the service, the offer of a Carers Support Plan and a named worker who will make direct contact with the carer within a three week time frame.

Anyone can make a referral to the Carers Centre either by phone, email or via the website and Community Hubs and there is a dedicated worker for each of the five localities.

### **What do we need to do?**



In order to achieve these outcomes for carers in Scottish Borders, and in line with the whole area approach, many services, interventions and organisations will need to:

- Be aware of carers needs and the Carers Act through training
- Identify and signpost carers to support
- Inform carers of their rights to a Carers Support Plans
- Invest in carers
- Recognise the expertise of carers
- Continue to maintain and develop support services

## How will we know we have made a difference?

Carers will say that they:

**Feel that they have improved health and wellbeing** – carers have opportunities to lead a fulfilled and healthy life. May include accessing support services, training and identifying what is important to them

**Can manage their caring role** – have support in place and able to have a life alongside caring if they wish to do so. Are able to continue with their caring role

**Feel valued by services** – carers will say that they have been identified, given a voice and feel listened to, understood and involved in planning and shaping services and supports required for the person they care for and themselves

**Are able to plan for the future** – carers will have improved peace of mind knowing that there is a plan in place in the event that they are unable to care. Carers will have the information they require to plan for the future.

**Have information and support to manage their finances and benefits** – carers will be given support and advice to maximise their income. They will know what they are entitled to and how to access it.

## When will this plan be reviewed?

Progress against this plan will be monitored through the governance structure and processes of the Health and Social Care Partnership Board.

The Carers Advisory Board will have a key role in monitoring the impact of the strategy.

The strategy will be reviewed at the midway point.

## Making it happen – delivering on our vision and outcomes

**Ambition 1: Improved health and wellbeing:** carers have opportunities to lead a fulfilled and healthy life. This may include accessing support services, training and identifying what is important to them

**The Action we will take:** We will provide information to carers in various ways across the Borders and raise awareness of carers' rights in order to identify and signpost carers to support. We will provide easy access to information through the Borders Carers Centre, community hubs and health settings across the Borders. We will identify how carers have been supported in order to improve our practice.

**What will success look like?** There will be an annual increase in the number of carers who have a carers support plan; from this the majority of carers will say their wellbeing has improved.

**Ambition 2: Can manage caring role:** Carers will have support in place and be able to have a life alongside caring if they wish to do so. They will be able to continue with their caring role

**The Action we will take:** We will provide information to carers on ways to take a break that works for them. This might be a local group or activity or more formal focussed support e.g. about dementia, mental health, parent carers.

**What will success look like?** We will have a short breaks statement in place by the end of December 2018 that will provide information about short breaks provision and access to it, and we will review the statement, and use of short breaks, at least annually with carers.

**Ambition 3: Feel valued by services** – carers will say that they have been identified, given a voice and feel listened to, understood and involved in planning and shaping services and supports required for the person they care for and themselves

**The Action we will take:** The Carers Advisory Board will be supported in having a voice by the Borders Carers Centre and carers will be represented at the Health and Social Care Partnership Board. Carers will be involved in the hospital discharge arrangements of the person they care for where appropriate. We will meet the new timescales to support carers where the cared for person is terminally ill.

**What will success look like?** Carers views will be taken into account in strategic developments that have an impact on carers and there will be increased referrals to the Hospital Liaison Service so that more carers have the support they require at the point of discharge.

**Ambition 4: Able to plan for the future** – carers will have improved peace of mind knowing that there is a plan in place in the event that they are unable to care. Carers will have the information they require to plan for the future.

**The Action we will take:** We will develop an anticipatory care plan with carers that links to the carer support plan. We will review the Emergency Carers Card with carers to ensure that we have an effective system in place. We will develop a future planning pathway and template.

**What will success look like?** Every carer will be offered the opportunity to make a future plan as part of their carers support plan. From this the majority of carers will feel more positive about planning for the future.

**Ambition 5: Finances and benefits** – carers will be given support and advice to maximise their income. They will know what they are entitled to and how to access it.

**The Action we will take:** Carers will be given support and advice on funding through the support plan discussion.

**What will success look like?** The majority of carers at review will feel positive about understanding and maximising their finances. There will be an increase in the number of carers accessing charitable grants and carers will be enabled to manage their finances.

#### **What Carers Say**

**Carers quotes taken from the annual evaluation Borders Carers Centre (BCC) 2018 and Health Needs Assessment (HNA):**

“I would not cope without respite” HNA

“It’s been very hard to get information and help in getting all benefits we were entitled to”

“Emotional support is very much appreciated” BCC

“I honestly can’t see how I would have survived the challenges of my life without ongoing support” BCC

#### **Karen’s story**

I’m a single mum, which makes things hard to begin with, but throw into that the fact that my wonderful daughter has complex and multiple needs, that makes life really hard. My daughter Amy is wonderful she has Phelan-McDermid Syndrome. My first problem was that no-one really knew what it was. It’s rare and a chromosome deficiency. It means that she has a learning disability, is practically non verbal, struggles to mobilise due to low muscle tone and is doubly incontinent and to add to that she never really sleeps! She is now 10 years old and it’s really hard at times and very special at others. She is loving and moody and brings challenges every day and we cope most of the time now but that’s just because at last I am not caring alone. When she was first diagnosed I needed information and I needed support but that was really difficult to get locally plus it was like everyone was speaking a foreign language. I had a few national helplines and great family and friends but just getting through the day was hard enough. My GP was good to talk to and Amy’s health needs are met but it was really the impact on me, that’s what I didn’t know how to deal with. I couldn’t help comparing my life with others “why us?”. I realised slowly that I just wasn’t coping, I was tired all the time, struggling with money, sick of appointments and referrals to here there and everywhere, sick of the battles with education and I started to withdraw from my friends and was becoming really isolated. It was my doctor who picked up on my mood and gave me a leaflet about the Borders Carers Centre. By this time I thought I would give anything a go. I called them and cried and cried. It all came out, when I look back now it was a big step for me but also the beginning of things getting better. Within a few days someone came to visit me and Amy at home and I was able to offload all of the stuff that had been going around in my head – the guilt, the frustration, the fatigue and the anger. The talking was exhausting but it helped. It took time it wasn’t a quick fix, but just by talking I could feel a weight lifting.

It's amazing what you don't know and it's amazing what can be done. It's still hard and challenging – it always will be but the difference now is that I know where to go for help, I'm not alone and it doesn't matter what the problem is the people at the Carers Centre will always try to find a solution. We have even had a trip to Eurodisney – it was a dream come true. The Carers Centre can't take the caring or the fatigue away but they can make it easier. I feel I can carry on now because I am not fighting on my own to get the best for Amy. I have a great team of carers and I can tell that they really care about Amy, and this means so much to both of us and it gives me just a bit of time to myself, even if it is just to catch up with the washing. I couldn't manage without it and I'm grateful for everything, I just wish it wasn't so hard. I worry about what the future holds for us but at least now I know the support and help is out there and that means a lot.

DRAFT