



When caring ends

Improving information and support for former carers

March 2017

Discussion group

Following on from Bolton Carers Support's Annual General Meeting (October 2016) when a former carer spoke about issues he faced following bereavement, a small discussion group was held on 8 December 2016 at Thicketford Centre, facilitated by Bolton Carers Support and Healthwatch Bolton.

Who are former carers?

Former carers are partners, relatives, friends or neighbours whose caring role has ended because of the death of the person they were supporting. Former carers may be of any age.

There is often confusion around whether a carer is 'still a carer' if the person they look after goes into residential care. Bolton Carers Support would argue that they are still a carer because of their continuing involvement in care, including:

- a strong sense of responsibility towards the person requiring care
- regular visits to see the person in the care home
- provision of emotional support
- monitoring of care being provided by the facility

While the provision of physical care is primarily being done within the care home and the caring role has changed, essentially the carer still retains that sense of responsibility, but may experience feelings of intense loss, guilt and sadness because they are no longer able to physically provide the care themselves.

How many former carers are there?

Carers UK, the national campaigning organisation, has estimated that 2.1 million people take on a new caring role each year, while just under 2.1 million people cease caring annually ('Need to know: transitions in and out of caring', Carers UK, 2014).

Bolton district	Number of carers Census 2011	Estimated number that begin caring annually	Estimated number that cease caring annually
Bolton North East	10,658	3,490	3,440
Bolton South East	10,758	3,530	3,470
Bolton West	10,869	3,560	3,510
Total	30,649	10,040	9,890

What issues do former carers face?

“Former carers also need support and advice, as they find themselves in a new and difficult situation. They may be grieving, they may have spent a long time out of the workforce, and they will often find that they quickly become ineligible for the benefits that they rely on to get by. Many former carers also have debts, built up after years of caring on low income. It is therefore important to make sure that advice, information and support is also available to former carers who may need help coping emotionally or financially, or who want to move back into work.”

(Carers UK, 2014)

Many former carers face common issues, including the following;

- **Grief / loss due to bereavement**

Grief following the death of the cared-for person can be overwhelming. While grief is experienced in a very individual way, former carers have described the grieving process as like *“a big black hole”*, a *“devastating sense of loss”* and that they *“muddle through life”* for some time after bereavement.

“I can identify with comments about isolation and loneliness following a bereavement. When I lost Mum, my social life was gone at the same time. Caring for her for over 20 years, I would talk to her all the time. Then, suddenly, she wasn’t there anymore.”

“Dealing with other siblings when you’ve been the main carer can be traumatic.”

“Men are not seen as having feelings.”

Cronin et al, ‘Between worlds: the experiences and needs of former family carers’, emphasised that former carers experience negative effects on their health, with financial problems and social isolation being particular issues. Cronin et al describe post-caring as a time of being ‘between worlds’ comprising 3 inter-related transitions:

- ‘loss of the caring world’
- ‘living in loss’, and
- ‘moving on’.

- **Loss of role / identity as a carer**

“While you can prepare yourself intellectually for someone’s passing, you can’t prepare yourself emotionally. People don’t understand the way it flattens you emotionally...somebody just pulls the rug out from under you. You’ve not only lost a person, but you’ve lost your ‘job’. You have been living in a parallel universe where the outside world has disappeared.”

“It’s a very strange feeling; previously you connected with life as a carer.”

“You cannot prepare for the emotional response; people you deal with often cannot imagine how you are feeling.”

Being a carer can be an all-encompassing role, with many carers giving up their social activities due to the demands of caring. After bereavement, the carer’s previously structured routine is lost, leaving a huge void which it takes some time to fill.

The International Longevity Centre UK (ILC-UK) February 2015 report ‘The emotional wellbeing of older carers’ found that:

- long-term caring was associated with poorer quality of life and life satisfaction for carers; and
- the end of a caring role was associated with increased depression amongst both male and female carers.

The research highlighted the reality faced by many former carers, including a high risk of emotional distress; the loss of friends either because of a lack of time to socialise or because friends were unable to properly understand the constraints and strains of caring; and potential health risks.

- **Isolation / lack of social support**

The end of a caring role is a significant transition point in the life of a carer. For carers who have been looking after a partner this can be particularly devastating, with the transition to living alone from being part of a couple increasing the likelihood of social exclusion threefold (ILC-UK, 2015).

“Isolation, loneliness and a disappearing social life have stopped me coming to carer’s events. The cost of caring can be significant and stops socialising opportunities and you end up not connected to the world around you.”

Emotional support: actions

- Bolton Carers Support's Support Group Co-ordinator to test out a peer support friendship group for former carers, with a focus on social activities as opposed to a 'support group'.
- Include information about CRUSE bereavement counselling and One Point Service – the umbrella organisation for all local counselling services – in Bolton Carers Support's Carers Contact Newsletter and in factsheet 9 'when caring ends'.

- **Employment issues**

Carers may have had to give up work to care, and experience difficulties re-entering the workplace following bereavement. During the time they have been out of the workforce, changes in technology and industry may mean some skills are out of date. Some former carers will face other barriers, such as age, in their attempt to re-enter employment. Changes to benefits mean former carers may face pressure to find work too soon after bereavement.

"My benefits stopped straight away."

"As soon as you ring up DWP – benefits stop. All they want to know is the date / time – and then you get a letter saying 'the deceased has been overpaid...'"

"Carers Allowance stops instantly so there's no money coming in. Then DWP letter saying 'we'll consider giving you this benefit for a short period of time subject to certain criteria'. You're just dumped. The Job Centre never sent a letter to follow on from this."

"We will consider giving you Job Seekers Allowance....". There was no offer to discuss the situation and no help offered. It wasn't recognised that someone in their 50's might have cared for a while and had no recent work experience when they were left without a caring role.

Employment / benefits: actions

- Through Bolton Carers Support newsletter, include articles about ‘planning ahead’ to raise awareness about changes to benefits following bereavement.
- Greater recognition from DWP / Job Centre that there’s a huge transition around when caring role ends – national issue – raise with Carers UK.
- Explore issues around carers and employment – hold a discussion group and gather feedback.

- **Financial disadvantage**

Former carers may have been on low incomes for many years while caring and this may also have affected their ability to save for the future. 70% of carers report that they were over £10,000 a year worse off as a result of giving up work, reducing their hours or work, or taking a lower paid job (Carers UK, 2014).

Carers and the person they cared for may not have realised the importance of making a will, which could also lead to significant problems following bereavement.

“Make sure everyone ...warn everyone to make sure there’s a Will and provision has been made. Bite the bullet and do something – at least you’ve done it. I was in the position of potentially being made homeless after caring for my Mother for many years. She didn’t have a Will so was intestate – we should have put the house in joint ownership.”

Making a Will: actions

- Through the Carers Contact newsletter, publicise Age UK’s helpful checklist of things to keep accessible for family members or friends following bereavement. Include computer passwords in this.
- Expand Bolton Carers Support’s workshops around making a will, planning for the future, power of attorney – e.g. ‘preparing for the unexpected’.

- **Poor health**

“Doctors may be a good place to act as a point of information for carers when it ends. There is the Annual Health Check for example. They need to be able to give information about what is available to help you cope at that time; perhaps some information about bereavement could go in the Carers Pack in the GP surgery. There is the notice boards as well.”

“There needs to be recognition that carers can experience anxiety and depression. It’s usually the result of trying to be far too strong for far too long. We need to let carers know that it is worth getting some help – whether that is medication, counselling, psychotherapy.”

The isolation experienced during caring may affect carers’ mental health and an intensely physically demanding caring role may have resulted in back injuries or illness. Some carers’ health improves once caring has ended, whereas for others there will be the onset of ill-health. Some carers say that they ‘hadn’t got time to be ill’ while caring, only to find they experience significant ill-health after caring ends.

Health: actions

- Bolton Carers Support’s Health Linkworker to ensure General Practice staff are aware of the emotional impact on carers following bereavement e.g. pick this up through annual health checks (include an information sheet on ‘supporting former carers’ in the GP Carers Resource File).

- **Dealing with practical matters**

“The bureaucracy hits you in the face in the first fortnight. My husband died suddenly – he had had MS for 25 years, but died of a heart attack. We all die but I was totally unprepared. My husband did all the work – finance, insurance, Motability car, all services, M+S card, Tesco card – all were in his name. Dealing with the banks was relatively easy – but others were a load of hassle. It was a huge rigamarole to reopen accounts in my name. Deeply, deeply stressful.”

“Carers want to contact someone who has the expertise, who is well versed in bereavement...want to have a named contact.”

“Because my husband died outside of Bolton (in Southport), the post mortem had to be completed in Southport. We couldn’t arrange his funeral immediately because it took some time for the post mortem to be done.”

“I was faced with two questions; how do I cope as an individual and secondly how do I manage all those things like the ‘utilities’.”

“It’s as though you could do with a checklist where you can keep all your information that you might need. It’s having to find all the relevant information.”

Dealing with practical matters: actions

- Expand the factsheet on ‘when caring ends’ to include clear information regarding the legal and formal processes following death.
- Use the newsletter to share information about the best way to communicate change of circumstances – e.g. for utilities, send letter and copy of death certificate.
- Identify which organisations (e.g. British gas) enable you to register on a person’s account as their carer – sharing information that may then assist when change of details are necessary later.
- Promote the hospital based bereavement team.
- Clarify in what circumstances a post-mortem could be requested / what rights are / process and time delay after bereavement if a post mortem is required. Clarity over the role of the Coroner’s Office.
- Publicise the fact that former carers can ring Bolton Carers Support can support former carers for up to 2 years following bereavement.

- **Carers looking after someone who has gone into residential care**

“Former carers include when carers look after someone who has gone into residential care. There are some places that are very good and encourage carers to stay involved in the person’s care, to do the things that residential care staff don’t have the time to do themselves, but others aren’t and carers feel their loss of role.”

“If someone goes into residential care it’s a kind of bereavement too. I wonder how the care homes look after the carers.”

Residential care: actions

- Recognition that this is a transition point similar to bereavement and ensure that carers are aware of how Bolton Carers Support can provide support through the carers helpline and information and advice appointments.
- Identify possible funding for specific work to support carers facing the decision to place their relative in residential care.

Next Steps

From March – December 2017, Bolton Carers Support will:

- Revise factsheet 9: ‘when caring ends’.
- Update BCS service leaflet to ensure support for former carers is included.
- Include a page on supporting former carers in the GP Carers Resource File.
- Review content on the ‘Planning for the Future’ workshop sessions to ensure some of the key points from the discussions are included.
- Include an article in June 2017 Carers Contact newsletter about ‘planning ahead’.
- Research possible funding sources for work around supporting carers at the key transition point of the cared-for person entering residential care.
- Test out a friendship group for former carers.
- Explore issues around carers and employment further: invite to attend a discussion group included in March 2017 Carers Contact newsletter.