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Respite care at Hospice at Home Carlisle and North Lakeland: what carers tell us about the service we provide.

Growing numbers of family caregivers provide vital care and help to family members, often over many years and for a variety of reasons. (Carers UK, 2021) They may have to cope with complex support needs and practical difficulties often on their own, at home. Those who are referred to Hospice at Home for respite care and support, are having to come to terms with the future loss of their loved one bringing concomitant emotional stress and sadness into an already exhausting and extremely demanding situation. It is vital therefore that family carers are adequately supported in order to protect their own health and well-being, enabling them to continue to care (ONS, 2021).

> ***"A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without***

The Covid 19 pandemic saw a significant increase in the number of people dying at home instead of hospital (Office for Health Improvement and Disparities, 2022). Many palliative and end of life care services reported being busier during the pandemic, with services and resources often shifted into the community to support more people at home. The number of carers reporting an inability to take a break since the pandemic has risen to 72% (Carers UK 'Breaks or Breakdown' 2021).

> ***"Respite means taking a break from caring, while the person you care for is looked after by someone else. It lets you take time out to look after yourself and helps stop you becoming exhausted and run down." (NHS, 2019)***

Hospice at Home Carlise and North Lakeland provides respite care by means of block visits during the day and overnight. As with all Hospice at Home services respite is provided free at the point of need. Over recent years we have noticed increased requests for respite care. In the financial year of 2019 – 2020 we provided 8,075 hours of respite care by day or night or a combination of the two. 128 patients were initially referred for respite only.

We wish to continue to provide a flexible respite service that is responsive to the identified needs of carers and their families/loved ones therefore, to this end we asked a volunteer sample of carers how they felt about the respite service we offer. We are extremely grateful to those carers who shared their experiences with us.

In order to protect the confidentiality of the participants, names used have been changed, and in addition, all names are deliberately gender neutral. Direct quotes from participants are used throughout the report, but the link to their particular caring situation has been concealed.

Of the thirteen carers who were interviewed, four were current carers in receipt of respite care and 9 had previously used the Hospice at Home service. Eight people had cared/were caring for a spouse or partner, four for a parent and one for an in-law. Length of time caring for their family member ranged from a few months to over twelve years – most had cared for at least two years. The shortest length of time someone had been in receipt of respite care was two weeks, and the longest two years. The majority had received respite for 3 to 6 months. The age range of carers was 48-87 and most were retired, not working or did not say. What follows are some key responses.

Respite Offered/Received

Most caregivers had received a three hourly block of time, generally once a week. Six had in addition received help overnight from 10pm to 7am – this was usually over the last week or two before the person they cared for had died. Some participants had been in receipt of respite care for only a few weeks, most for three to four months and three for between one and two years.

Flexibility and Notice

Respite was offered with varying degrees of notice, a week in advance, the day before, or on occasion at the last minute, especially if there had been a cancellation. Half of carers reported being happy to accept respite at short notice, with carers who were not working agreeing that they had flexibility themselves and so found it easier to accept a block of time at short notice or at different times and days. Just under half of carers would have appreciated a little more flexibility. A few carers who were working outside the home found it more difficult to use respite offered with little

"More choice would take us from 99% perfect to 100% perfect."

"I tell them about a hair appointment and they try and arrange care for that time."

notice whilst those working from home were more easily able to accommodate it.

Most carers felt that Hospice at Home tried very hard to give them respite hours at a time to suit – with a couple of carers highlighting specific instances where Hospice at Home had arranged respite so that they could attend an appointment.

Amount of Time offered

The majority of carers felt that three hours was usually the right amount of time to be away during the day, but five carers who lived more rurally would have liked a longer block of time. For those living in particularly rural locations it was impossible to get to the nearest town and back within three hours, thus limiting where they could go and who they might be able to meet. One or two carers said they would have liked a much longer block of time occasionally so that they could have travelled to see family who lived further away. One person said she was not sure what options were available regarding respite care.

A few carers reported anxiety at leaving the person they cared for. For these carers, three hours could sometimes feel like too long and they would return home before the three hours were up, the other carers made use of the respite hours, but did not leave the house, preferring to go into another room to rest. Whether they felt they could leave the person and go out or not was often dependent on what sort of day it had been, or a sense of guilt that they were leaving the person. One or two of the people being cared for were extremely reluctant to be without the person caring for them.

Overnight Respite Care

Overnight respite care was viewed very positively by the six people who had received it. It gave carers a break from round the clock caring, especially in the last few weeks of life of the person they cared for. Carers expressed profound gratitude for the professionalism, kindness and often continuity provided by staff they had come to know well. Carers felt that the service tried very hard to give them support hours during these challenging times, even when it was clear that they had limited support staff availability

"On the night he died, the nurse took over and she was brilliant. I wouldn't have coped without Hospice at Home, even though I have a supportive family. H at H helped me when no-one else could"

"I can't fault the Hospice at Home care, all the staff were fantastic, even the people on the phones. You could tell they were stretched, particularly for overnight care. More resources are needed."

Most of these six carers had a combination of overnight plus a day-time block of care. The amount of care increased as end of life approached.

How Carers Used Their Respite

The majority of carers enjoyed some time away from the home and their caring responsibilities. For some this still meant staying close by, taking time out to walk the dog, read a book or just putting their feet up and having a rest.

Some people were reluctant to spend any time away from the person they cared for, and this was more apparent as the person moved toward the end of life. Respite time was often spent in the home catching up with some sleep.

"It let us get some sleep at the end. We didn't want her left on her own. We never left the house."

Other carers took the opportunity to go further afield. Perhaps shopping, going for a coffee, or getting their hair cut. A chance to go into the nearest town, or for one working carer to go into the office. Excursions were limited for those living more rurally, who were often too far away from the nearest town to access it within a three-hour slot.

"I've sat in the car round the corner and read a book. It's hard to go further afield. It's about one and a half hours to get anywhere."

"It's *me* space. Escapism"

A few carers preferred this respite block to be 'me time'. Time spent alone was an opportunity for space to think and switch off.

Carers enjoyed spending time with family and friends - although this had proved difficult to do during the pandemic lockdowns and for those with family living further away, three hours was not enough for them to arrange a meet up.

One woman described the joy of having a block of time in which she could choose a range of options – catch up with a friend, go to the hairdresser, go shopping or just out for a walk. She relished the chance for a bit of 'normalcy' for a few hours.

"The few hours away are heaven. It brings me back into the realms of normality."

Respite Care Service Provided by Hospice at Home

"fantastic" "godsend" "lifesaver"

"amazing" "terrific"

Carers were almost all overwhelmingly positive about the respite service they had received from Hospice at Home. Carers praised not only the support staff who came to their home, but also the office and administrative staff who answered the phone.

"All the staff were fantastic, even the people on the phones"

Most carers articulated a strong sense of gratitude, this was often expressed in terms of 'friendship' with the Hospice at Home team and when a loved one had died, many carers said they had asked for donations to Hospice at Home at the funeral. This was viewed as a way of marking their thanks and appreciation.

'I wouldn't have coped without Hospice at Home…..they helped me when no-one else could'.(Kit)

"I'm so pleased we're getting anything. So I don't want to push it. I would be worried about services being taken away. I don't want to rock the boat."

A few carers expressed some anxiety about appearing critical of the amount of respite care they had received. This was generally not because of the quality of care or the service they had received but because they were so grateful for the help and didn't want to say anything which might indicate otherwise, for fear of losing the service. Three interviewees indicated that they had had one person from Hospice at Home whom they had found 'unsuitable'. Rowan had worried about complaining but found that Hospice at Home *'were very nice about it'* when she did.

"One person was depressed, but that was the exception"

Contacting Hospice at Home if a family carer missed a call, was made more difficult because they could not use phone back on the number used to call them. One carer considered the Hospice at Home leaflet was in need of an update – too much dense print rendered it not user friendly.

Hospice at Home – not just respite care

It was clear that Hospice at Home provided more than just the respite itself. Respite care hours offered families a chance to talk and unburden often complex and difficult emotions to people who they grew to know as friends, and whom they trusted. In addition, respite carers offered an outside and detached viewpoint which brought comfort to families. A few carers had felt in conflict with doctors and health professionals, or were confused by bureaucracy and the multiplicity of people and services Hospice at Home often acted as the 'go to' people of continuity and information when situations were challenging.

Respite at Home

Almost all the participants described difficulties when outside agencies, including Hospice at Home first began coming into their homes. For some, particularly those who are very private, allowing strangers into the home can be extremely challenging.

"It was very hard to begin with, as… is a very private person"

"It can feel like an intrusion, but everyone has been respectful."

Giving and receiving of personal care by someone unknown could be especially hard. One or two carers expressed a need to continue doing this as long as possible, especially spouses and partners. Those caring for a parent could sometimes find personal care more difficult to provide

"For dignity, I'm glad the carers washed Dad. He wouldn't have wanted me to do it"

Almost all carers praised the Hospice at Home carers for making this easier. Most described warm friendships, continuity of support (which was so important) and strong feeling of trust, growing between themselves, the person being cared for and the Hospice at Home staff.

"The girls who come in are friends. Whoever interviews them does a great job!"

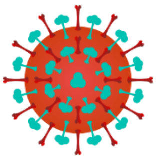
Emotional Challenges - Providing and extra pair of eyes

Carers expressed a range of emotional responses including guilt, anger, frustration and deep sadness. Over time, as the illness of the person they cared for progressed, carers emphasised again the mportance of the continuity provided by Hospice at Home.

“someone coming in is more detached, an extra pair of eyes.”

“Having people to talk to was invaluable. I never felt the carers were intrusive in anyway” (Bren)

Covid Pandemic



Every interviewee discussed the impact that Covid 19 pandemic had had on their caring experience. This impact was often profound, continuing even after the death of the person they cared for. Many carers lost the support of other family members and friends – almost entirely, at the peak of the pandemic and during the strictest lockdowns.

“All the staff sanitised and wore masks”

For half of carers, Hospice at Home or other paid professionals were the only people they saw during this time. Vulnerabilities and lockdowns limited the places they could go and the people they could see. This left them feeling more reliant than before on this support. Carers were particularly grateful for the protective measures care staff took to minimise the risk of Covid transmission.

For one carer the support and care provided from Hospice at Home and other agencies had allowed their loved one to stay at home, even under the most challenging of circumstances.

“With help from Hospice at Home, and other agencies, we were able to allow him to stay at home, in the midst of a lockdown and Covid. He was fortunate to be able to die at home, not frightened and alone in hospital, and for that I am

For a few carers accessing their GP proved difficult, appointments were often over the phone and time limited. Sammy was relieved when the person she cared for agreed to carers coming in, as they provided a reassuring ‘pair of eyes on Dad’ when no other help was coming in.

“Hospice at Home took all the pressure off.”

Hospice at Home staff were often able to provide the information that carers needed and the trust brokered by continuity of care enabled them to listen, support and advise when carers felt overwhelmed.

Hospice at Home support was able to give a holistic, whole family care approach, which was predicated on ‘listening’ rather than telling. Carers who were under considerable stress, and worrying about difficult decisions were able to talk to respite carers

'Sometimes they were counsellors for me. They would listen….just what I needed". (Bren)

"I'd been having a bad day. Hospice at Home were lovely. Excellent. A godsend."

A few participants told of upsetting situations in the last days, when services were stretched, or pain relief was inadequate. Despite this, the respite care provided by Hospice at Home remained effective, important and on one occasion the sole redeeming factor.

Respite and support services offered one carer the opportunity to spend quality time with the person they cared for in life and good counselling allowed them to cope in bereavement.

One carer expressed disappointment that Hospice at Home had not followed up after sending her a card about counselling.

Summary

Growing numbers of people are living longer with increasingly complex medical and cognitive difficulties and life limiting illnesses and more people are choosing to die at home. Family carers we spoke to wanted to care for the person at home, but the caring role could be physically and emotionally exhausting. Home can come to resemble a 'mini care home', with equipment, medical paraphernalia, paid carers and other professionals in the house, sometimes both day and night. Preparing for such a scenario when diagnosis is first given can be almost impossible.

Most people interviewed expressed unease in the early stages when people first entered their homes to provide support and care, but Hospice at Home Carlise and North Lakeland staff often came to be regarded as friends, counsellors and a source of comfort. There were overwhelmingly positive views of the respite service provided; both support staff and administrative staff were praised for their caring attitudes, professionalism and dedication. Most interviewees expressed profound gratitude for the help that they had received.

The majority were happy with the amount of respite care offered, but some would have liked the option of longer sessions to enable them to visit family or the nearest town. This was most apparent for carers who lived in rural areas. A few carers would probably have liked extra respite block hours but were reluctant to ask for anymore when they knew that services were stretched, or that they would appear critical. Additional flexibility and notice for respite care would have been beneficial for some carers, particularly those who were working.

Respite overnight when the person being cared for was reaching end of life, provided carers with an opportunity to rest and sleep at this most difficult time. Carers emphasised the knowledge of Hospice at Home respite carers borne of experience, the importance of continuity of care and that they felt 'safe' with these staff which allowed them to take this much needed rest.

Respite care staff were often viewed as a 'detached' pair of eyes and ears. When families were in disagreement with health professionals, Hospice at Home staff were able to listen to carers concerns and provide an unbiased continuity of support which was clearly beneficial.

Bereavement and the grieving process has been severely affected by the pandemic. Hospice at Home staff have offered bereavement counselling to most carers. This service has the potential to become more important as people begin to move forward post pandemic taking with them a 'complicated grief'.

> ***'It is important to recognise that wherever 'the person' is referred to in the Ambitions Framework (The Ambitions for Palliative and End of Life Care: A national framework for local action), this relates both to the person who has the advanced life limiting illness as well as their carers, families and those important to them.' (NHS, Renewing our Ambitions for Palliative and End of Life Care, 2021)***

Many carers were reliant almost entirely on Hospice at Home to get a break from their caring role. It was evident that most carers did not have criticisms of this service and were profoundly and expressively grateful to Hospice at Home for the support and care they and their relative had received. There is a risk, often implicitly voiced by participants, that carers might be fearful of complaining or raising concerns due to anxiety of expressing anything negative for fear that the service might be withdrawn. Carers who *had* raised a complaint were actually very happy with Hospice at Home's response and the resolution of the problem. Carers might also be reluctant to ask for *extra* respite hours because they perceive the service to be stretched and thus fear of losing the service they have, makes them refrain from requesting any additional hours.

In conclusion, the interviews with cares show that Hospice at Home Carlisle and North Lakeland provides a much needed and valued respite service to carers and people with life limiting illnesses. It is our ambition to offer a dynamic, supportive, and bespoke service which caregivers can access when they need it most, bringing elements of hospice philosophy into the home.