

# Better Care Personas



Produced by  cxpartners

## Carers



### Jane, 44

Has been caring for her Dad for 5 months  
New to caring

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### John, 76

Has been caring for his wife for 53 years  
Managing mental illness

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### Amir, 33

Has been caring for his mum for 1.5 years  
Specific cultural needs

## Service users



### Sarah, 60

Is new to the care system & living at home  
Proactive in care planning

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### Bill, 71

Long term care user in sheltered housing  
Passive in care planning

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### Tom, 58

Has been using care at home for 2 years.  
Passive in care planning



## Jane, 44

Has been caring for her Dad for 5 months  
New to caring



*It feels like they're putting responsibility on the carers - this amateur has to decide what a professional should be doing.*

Jane's thoughts on independence and wellbeing

### How long have they been caring for



### Knowledge of the care system



### Other Responsibilities (Work and family)



### How is their own health



## Trigger

Jane has been caring for her dad, Peter (77), for the last 5 months after he had his leg amputated as a result of a major infection following a UTI. Jane's dad lives with her mum (74), 10 minutes drive away from Jane.

## Change in my situation

Jane has a family of her own and used to live a couple of hours drive away. After her dad became ill she decided to relocate the family. Jane works from home part time. She has informed her boss about her situation and he has been very understanding. Jane has had to take on a lot of responsibilities since her dad left hospital, and is not sure how long she can carry on like this.

## Planning care

Jane is completely new to the care system and is still trying to navigate her way around it all. "It's an area you know nothing about. It's very complex and very divided."

When Jane's dad was in hospital, Jane was told by a hospital social worker that the only option for him after he was discharged was to go into residential care. Jane was devastated because her dad values his independence so much. Some time after this, Jane found out from a friend that this was not the case and that care in the home could be provided during the night as well as during the day. Jane was 'furious' that she had been misinformed and not made aware of all of the options available. Jane has spoken to the lead hospital social worker, who seemed nervous about the complaint becoming public and has arranged for a review to take place in the near future.

Her dad is temporarily set up with a care provider that was put in place following his stay in hospital by the STAR team. Jane's dad receives 2 care visits a day. He has some savings, so for the time being he is self-funding. She is currently trying to find a care provider that she feels will provide good quality care for her dad, and that will remain the same once his money runs out. Jane has been given a list of care providers by a social worker and told to research them herself. No support has been given in making this choice. She feels that she has 'fallen off the radar' and does not have enough information to make an informed decision.

"Trying to find a decent care provider is one of the most difficult things I've experienced. That list should not go out with inadequate names on. One of them is rated as in need of improvement, and the 2 they're going to use for North Bristol aren't even up and running! Right now I'm feeling desperate. I'm thinking now I've just got to get anyone, someone who has the capacity but is not inadequate. How bad is that."

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***For dad, independence is about him carrying on what he was doing before he fell ill. He still wants to do those things but is too scared to do them on his own and is worried about people looking at him.***

Jane's thoughts on Independence

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***Is it going to end up with people just getting pushed out, putting money in the bank? Is it leading to people like me sorting it all out, doing the council's job for them? It's not making it easier..***

Jane's thoughts on BCC's future plans

## Caring

As well as caring for her dad Jane has to keep an eye on her mum, who has type 2 diabetes which is managed by diet. Although her mum does not require professional care, Jane does need to prompt her mum to eat the right foods. She is concerned that her mum might be suffering from mild dementia.

Jane is having to keep track of and chase appointments with the various people involved in her dad's care. No one else is managing it and she feels that the responsibility lies entirely on her shoulders.

Although her boss is very understanding, Jane is finding it difficult to juggle responsibilities with work, her own family and her dad. She has very little time to herself and has had to give up the social activities and hobbies that she used to do. "It's kind of taken over my life."

Jane's dad was very independent before the amputation. He used to attend their local church, go shopping in the local markets, and tend to his small allotment where he used to grow vegetables. Since having his leg amputated he doesn't go out because he is worried that people will look at him because he is in a wheelchair. Jane has noticed that her dad is becoming depressed, and doesn't know what to do about it.

## Reviewing care

Over the last 5 months Jane's dad has had some bad experiences with the carers who have been put in place. The carers that visit him are inconsistent, and he doesn't know in advance who is going to be coming. Sometimes the carers haven't turned up. Jane now has to phone every day to check they have turned up. Sometimes the carers rush him which causes him to become confused and agitated which is stressful for Jane. He seems to get on better with carers who are closer to his age who share his sense of humour.

Jane has been trying to get funding for incontinence pants for her dad. She has to chase the incontinence team, who still haven't got back to her. She is having to buy the Tena pants herself which are costly.



## Jane, 44

Has been caring for her Dad for 5 months  
New to caring

### Re-write the story

#### Trigger

Jane has been caring for her dad, Peter (77), for the last 5 months after he had his leg amputated as a result of a major infection following a UTI. Jane's dad lives with her mum (74), 10 minutes drive away from Jane.

Jane's mum has type 2 diabetes which is managed by diet. Although her mum does not require professional care, Jane does need to prompt her mum to eat the right foods. She is concerned that her mum might be suffering from mild dementia.

#### Change in my situation

Jane has a family of her own and used to live a couple of hours drive away. After her dad became ill she decided to relocate the family. Jane works from home part time. She has informed her boss about her situation and he has been very understanding.

#### Change in my situation

When Jane's dad was in hospital, a meeting was arranged with the hospital discharge team for her, her mum and her dad to discuss their needs for when her dad was discharged. Jane and her parents felt that they needed time to process what had happened before making any big decisions about her dad's care. Two carers from the STAR team were assigned to visit Jane's dad at home starting from the day he was discharged. It was arranged that they would visit twice every day.

They were also introduced to Sophie, the Care Coordinator that had been assigned to their family. The hospital discharge team explained to Jane and her parents that a Care Coordinator is someone who helps people to navigate the care system and will be able to put them in touch with the right people at the right time. Jane is completely new to the care system, so it was a relief to find out that Sophie would be helping them along the way. They were told that their social worker was called Kate, and that she would be visiting them in two weeks time, along with Sophie, to discuss Jane's dad's care option.

Two weeks later Kate came to Jane's dad's house. She talked with Jane, her dad and her mum about their needs, likes and dislikes and their wishes. She looked at the family holistically and identified where support was needed for each of them. Jane was given a carer's allowance, and respite was put in place to enable Jane to get a break when needed without her having to worry about her dad. They also gave the family advice about diabetes for Jane's mum, and arranged for a dementia nurse called Liz to visit every other week. The key details of the assessment were shared with Sophie, so that she could sign post the family to all of the services they might need.

Kate gave Jane and her parents a list of care providers to look at for her dad's care, and explained that many of them have an online review system where members of the public can leave honest reviews about the care given, as well as read official reviews. The family learnt about gold star standards and felt reassured that the quality of care from these providers would be of a consistently excellent standard. Sophie let Jane and her parents know that if they have trouble finding a provider they feel happy with, Sophie can put them in touch with a brokerage service from the council that will assist them.

Jane's dad has some savings, so for the time being he is self-funding. Jane was concerned that when his money runs out the provider will change. Because it could not be guaranteed that Jane's dad would be able to continue with the same care provider once his care was government funded, a plan was put in place for a review of his needs and a review of the available care providers in advance of when the money runs out.

Jane and her parents were shown how to access online resources that could help them to learn a bit more about the care system. Sophie reassured them that if they had any questions that they couldn't find the answer to online, or that they didn't understand, they could always come to her so that she could put them in contact with people who could help them.

A week later an occupational therapist came to Jane's dad's house to assess the home, which was what Kate had recommended following their meeting. They suggested adaptations to her dad's bathroom, and to his bedroom. She also suggested that they apply for funding for a lift, so that Jane's dad can go upstairs and not be limited to the downstairs floor only. The details were shared with Sophie so that she was kept up to date.

## Caring

Jane arranges and keeps track of her dad's appointments with the various people involved in his care. Sophie keeps a record of all of Jane's dad's care needs and the wishes of the family and is able to share this with other services. This means that Jane doesn't have to repeat her dad's story at each appointment, and she isn't having to keep track of all of her dad's requirements and relay these to each service. Jane feels supported and as though her and her family are in good hands.

Because of the support that has been provided throughout, Jane has been able to continue seeing friends and carrying on with her life. Her dad has also felt empowered through being involved in his care planning, and has been able to continue with social activities that he used to.

Jane and her parents feel positive about the care that is being provided. Jane's dad likes the carers that visit him, and the family feel that he can rely on them to provide quality care and to look out for her dad's best interests. Jane feels that she will be able to continue caring for her dad going forwards, because of the consistent support that they all continue to receive.



## John, 76

Has been caring for his wife for 53 years  
Managing mental illness



*I know Lesley's illness inside out. I know when she needs help urgently and I want to be believed that this help is needed.*

John's thoughts on caring for Lesley

### How long have they been caring for



### Knowledge of the care system



### Other Responsibilities (Work and family)



### How is their own health



## Triggers

John has been caring for his wife, Lesley (74), for the 53 years that they have been married. Lesley has bipolar, mild dementia and poor mobility since having a knee and hip operation. Lesley has some cognitive impairment due to being given EST when she was younger. John and Lesley live in their own home together. John and Jane have a daughter called Penny. She used to help out quite a bit, but these days the care falls more on John because Penny has work commitments, a family of her own to look after and has had some health issues over the last year.

## Caring

Lesley's care is provided through means tested contributions. She attends a day centre twice a week. Here she gets to do gardening, play the piano and sing, and go on day trips which she really enjoys. The daycare was added to Lesley's care plan following a stay in hospital a few years ago. This gives John a little bit of time to himself, for which he is grateful.

The community dementia nurse visits once a month to see how Lesley is getting on. John is happy for the help because he feels out of his depth with Lesley's dementia.

Sometimes Lesley is very high and sometimes she is very low. There are certain behavioural signs that occur leading up to a manic episode, for example gardening during the night and singing. Lesley is very good at hiding these signs when their psychiatrist comes to the house to assess her. John has to keep very aware of the way Lesley is acting, because the earlier he can spot the signs the quicker an intervention can be made. Their psychiatrist is good at keeping Lesley's episodes in check. However it is sometimes hard to get hold of him, particularly at the weekend.

Lesley enjoys the singing and gardening that comes with her highs, and she giggles when she talks about it. But John hates it when she starts doing these things because he knows what it is leading up to. Sometimes people don't believe him that Lesley is leading up to an episode, because she hides it so well to others. This upsets John. Having to remain so alert for so many years takes its toll on John and he feels physically and mentally exhausted. "I know Lesley's illness inside out. I know when she needs help urgently and I want to be believed that this help is needed."

There have been times when John has been unable to access support during a crisis, and has had to physically restrain Lesley himself. John wishes that he could self-refer Lesley to speed things up. "I'm the one who knows Lesley best. I wish I could self refer so we could keep an episode from reaching crisis point. By crisis point we can never get help quick enough, unless we section her." Leading up to an episode John doesn't get much sleep because he is having to keep an eye on Lesley, who often wanders the streets at night or sings in the garden. He worries about her safety during these periods.

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*The Hub helps with my wellbeing. I get to see people, go on day trips. I do art at Callington - pottery, and I get to make music. I enjoy being helpful to other people. Making cups of tea and showing people where things are.*

*I don't want to 'go away'.*

Lesley's thoughts on independence and wellbeing

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*I don't know what part the council play in her care. Social workers I suppose but they've not been great.*

John's thoughts on BCC's involvement in care

John attends a carers support group at the Vassells Centre now and again. He'd like to go more frequently but it's hard for him to get to. Recently a member of the group told him he might be entitled to a carers fund to give him a break each week. He hasn't looked into this yet.

John has arthritis, which makes it hard for him to do all the things around the house that need doing. When he is able to get a sitter, and when his arthritis allows him, he likes going to dances that are held once a month - particularly Rock 'n' Roll and Jive. Lesley and John used to go together before Lesley's hip and knee operation and before the dementia, but he now has to go on his own.

### Reviewing care

Sometimes John feels he needs a break, and has arranged respite for Lesley. On a few occasions, John has been let down by the respite providers, which has meant that he has had to cancel his arrangements at the last minute.

John used to be able to arrange respite through his social worker. Now he has to phone up Care Direct who liaise with social workers and the respite providers. He has found that this leads to mistakes because there are too many parties involved. "It was easier when you could arrange respite directly through a social worker. With Care Direct there's too many people involved."

Recently, the day before he was supposed to leave for a trip, he called the care provider to check that everything was definitely booked. After liaising with the 3 parties involved in arranging the respite, John found out that the care was not in place because they still needed to carry out health and safety checks and to re-assess Lesley's condition. These kinds of experiences have made John wary of trying to arrange respite in the future, because he is worried that he will be let down again.

A care plan review was arranged during the time when Lesley was at Callington Road, which John attended. Lesley was not present.

John put her on the waiting list for a residential home because he felt that he couldn't carry on caring for her any longer. At the last minute he changed his mind before she was discharged because he felt uneasy about it. This was largely because Lesley has suffered abuse in institutions in the past and he was worried this might happen again. He had promised Lesley that he would always look after her, and couldn't bear to think of 'putting her in a home' even though life at home is becoming unmanageable. "I got upset and lonely and wanted to try caring again for Lesley."



## John, 76

Has been caring for his wife for 53 years  
Managing mental illness

### Re-write the story

#### Trigger

John has been caring for his wife, Lesley (74), for the 53 years that they have been married. Lesley has bipolar, mild dementia and poor mobility since having a knee and hip operation. Lesley has some cognitive impairment due to being given EST when she was younger. John and Lesley live in their own home together.

#### Caring

John and Lesley were assigned a Care Coordinator called Tina last year. Tina provides them with a single point of contact who can refer them to the right services at the right time. This was a relief to John who now has someone he can contact when he's in need of more support.

Lesley's care is provided through means tested contributions. She attends a day centre four days a week. Here she gets to do gardening, play the piano and sing, and go on day trips which she really enjoys. This gives John the opportunity to rest, see friends, go dancing, or do shopping and other household chores. !

The community psychiatric nurse visits once a week to see how Lesley is getting on, as well as the community dementia nurse. John feels supported and reassured by their regular visits. If the nurses notice a change in Lesley's behaviour, they can contact Tina to flag that extra services might be required.

Sometimes Lesley is very high and sometimes she is very low. There are certain behavioural signs that occur leading up to an episode, for example gardening during the night and singing. The earlier these signs are spotted the quicker an intervention can be made. When Tina was first assigned to John and Lesley's case, she was made aware of these behaviours. Tina has regular phone calls with John to check how things are going, and to be able to refer them to the appropriate mental health services if they feel that Lesley is heading towards a crisis. If John spots these signs in-between their catch ups he can get in touch with Tina, who will flag it with the appropriate teams. John feels that he is listened to, and likes the fact that he is working together with services.

John takes the free shuttle bus to a carers support group at the Vassells Centre once a week. John feels that this support helps him to deal with any emotional difficulties he might be experiencing, and he learns a lot from other members of the group and from courses that he sometimes attends.

When Lesley is leading up to a crisis and is up during the night, John can get in touch with Tina who can refer John for respite care so that he can have some support during the night to make sure that Lesley is safe. This allows John to get some rest during these difficult times.

When Tina first met John and Lesley, they talked about what life was like for John. Tina made John aware of how much respite he was entitled to, so that regular respite could be added to their care plan, in addition to respite for Lesley during a crisis. Tina put them in touch with a Social Worker who worked with them to find out what would help improve John's wellbeing. John was struggling with keeping up with the cleaning and general maintenance of their home because of his arthritis. Since he made the Social Worker aware of this, some help with cleaning and odd jobs has been arranged, which allows John and Lesley to continue living in their family home together.



## Amir, 33

Has been caring for his mum for 1.5 years  
Specific cultural needs

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*My mothers community and culture is everything to her. When my mother is happy I am happy.*

Amir's thoughts on independence and wellbeing

How long have they been caring for

0 (Months) 55 (Years)

Knowledge of the care system

Still working it out Very aware

Other Responsibilities (Work and family)

Low High

How is their own health

Good Bad

### Trigger

Amir has been caring for his 75 year old mother Fadiyah for the last year and a half, following the death of his sister.

Amir's sister moved in with Amir's mother when their father died 7 years ago. She helped her mother to prepare food, washed and showered her, helped her get to the toilet and took her to the mosque and social events in the community.

Amir's mother has type 2 diabetes, mobility issues and is becoming forgetful. She is from Pakistan and speaks Urdu, she can understand English but has trouble speaking it.

Before Amir's sister died he visited his mother a few times a week, mostly at the weekend due to work. When his sister died suddenly, Amir and his mother's lives were turned upside down.

### Change in my situation

Amir realised he would have to stay with his mother and help her as his other brother lives overseas. Amir found this difficult as he was used to living by himself and being able to socialise when he wanted to. Until living with his mother he had not realised how much his sister used to do for her.

Amir works full time but his work allow him to work flexible hours.

### Caring

Amir wanted to make some adjustments to the bathroom at his mother's house. He tried to get hold of the council department but never spoke to them because the waiting time was too long when he rang. He made a complaint but hasn't heard anything yet.

Amir is not able to take his mother out to social events and the Mosque in the week because of work.

Amir's cousin Dina used to help Amir's mother when his sister needed a break. She still visits Amir's mother and helps her out with personal care some mornings. However she has a cleaning job and the hours can be unpredictable. Amir's mother is very fond of her. She speaks Urdu and knows how she likes things done and never rushes her.

Over the last year Amir's mother's mental health has begun to deteriorate. She has become increasingly isolated and doesn't see the point of getting up some days. Amir is trying to do the best for his mother but the pressure is beginning to get to him. He doesn't have much time to see his friends and the impact of his sister's death is causing him to feel depressed.

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*I have no independence anymore. I still go out and see my friends but I can't do what I want when I want anymore.*

Amir's thoughts on independence and wellbeing

## Reviewing care

Amir had a holiday coming up and contacted his GP to see if there was anything he could do to get care for his mother whilst he is away. His GP told him to call Care Direct. Amir called Care Direct and an assessment was arranged along with an interpreter.

During the assessment the assessor asked his mother questions about her personal care in front of Amir. Amir's mother was embarrassed and neither parties were able to properly describe his mother's needs to the assessor.

The social worker has been back in touch to say that it will be easiest for Amir's mother to go to a respite home whilst he's away. Amir is very anxious about his mother having to stay somewhere else away from people who speak her language. He is considering cancelling his holiday as he doesn't feel he can do this to his mother.

Amir is feeling very anxious and isolated and is unsure how he will be able to cope in the future.



## Amir, 33

Has been caring for his mum for 1.5 years  
Specific cultural needs

### Re-write the story

#### Trigger

Amir has been caring for his 75 year old mother Fadiyah for the last year and a half, following the death of his sister.

Amir's sister moved in with Amir's mother when their father died 7 years ago. She helped her mother to prepare food, washed and showered her, helped her get to the toilet and took her to the mosque and social events in the community.

Amir's mother has type 2 diabetes, mobility issues and is becoming forgetful. She is from Pakistan and speaks Urdu, she can understand English but has trouble speaking it.

#### Change in situation

Before Amir's sister died he visited his mother a few times a week, mostly at the weekend due to work. When his sister died suddenly, Amir and his mother's lives were turned upside down.

#### Planning care

Following his sister's death Amir received a call from a lady called Zara from Dhek Bhal. She invited Amir to come in to talk about what they might be able to help him and his mother with since his sister's death.

When Amir met with Zara she talked through with him how he was feeling and what his mother's circumstance was. She suggested ways in which Dhek Bhal might be able to help with care and also social groups that were available to both him and his mother.

She explained the care assessment process and arranged for an assessment to take place at their home with an interpreter. During the assessment Amir was asked to leave the room when they talked about personal care so that his mother could be frank and talk about her needs openly.

Following the assessment a care plan was put together with Dhek Bhal, Amir and his mother. They let him know how much funding his mother had and talked through the type of things his mother could spend it on. They agreed that Dhek Bhal would visit 4 times a week to help with meals and 2 mornings to help with personal care. They talked through direct payment and helped Amir to set this up with WECIL so that they could employ Dina to come 5 mornings a week to help his mother with personal care.

Social visits to Dhek Bhal were put in place so that his mother could visit a women's group at the centre twice a week. Amir was also offered a carers funding allowance - with this he was able to pay Dhek Bhal to come and do a sit in service for 3 hours a week so he can get things done such as shopping. Amir also accesses a young carers group at Dhek Bhal which has been a lifeline and helped him deal with the emotional impact of his sisters death and caring for his mother.

An occupational therapist visited his mother's house and saw that her bath was inadequate for her needs. She helped Amir apply for a wet room to be installed. His mother was involved in the process and helped pick the tiles for the wet room. It took 3 months to have the wet room installed but the Council sent letters to inform them of the progress. Amir and his mother were very happy with the communication they received.

Amir was able to continue living in his own home, but visits his mother most evenings.

## Caring

Although losing his sister has left a hole in both his and his mother's lives, they have been able to retain some sense of normality thanks to the care provided. Attending social events at Dhek Bhal has been vital to their well being and given them a sense of purpose.

Amir has a holiday planned at the end of the year. Dhek Bhal have arranged a respite package for when he goes away and they were able to get extra funding to increase Dina's hours whilst he's away.



## Sarah, 60. Widowed.

Is new to the care system, living at home  
Proactive in care planning

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*Independence is something that I'm striving for, which my illness is taking away from me. It's about having control and opportunities.*

### Sarah's thoughts on independence and wellbeing

#### How long have they been caring for



#### How engaged with their care are they



#### How vulnerable are they



#### Independence before illness



#### How much of a support network do they have



### Trigger

Sarah was diagnosed with MS 6 years ago. Before the illness, she was very independent and worked full time. She has since had to give up work. She has poor mobility a lot of the time and usually has to use a frame to walk.

### Change in my situation

Sarah and her husband lived in rented accommodation together. Sarah's husband cared for her up until his death 4 years ago. This was quite a relief to Sarah because her husband was abusive at times. She likes the peace and quiet that she now has.

After her husband's death Sarah was in shock and could no longer afford to pay the rent by herself. This caused her MS to flare up very badly. She spent a week in hospital because she was unable to care for herself. Following this she moved in with her sister for a year.

“Everything imploded at that point in my life. It took a lot to pull myself out of that hole... I felt so sad, depressed, in pain, and angry about being in that situation. I didn't feel as though I deserved to be so stripped of my regalia, my home, security or hopes for the future.”

Sarah became depressed and this put a strain on their relationship. Sarah moved out of her sister's house and into a council flat on the fifth floor. The move from rented accommodation to social housing has been quite hard for her to adjust to. When the lift breaks she is unable to get out of her flat until it is fixed. She wishes she was able to get more fresh air and had access to a garden, but is grateful that she lives in a safe environment. She is very house proud and likes her flat to be clean and tidy. Since Sarah moved out of her sister's house, they don't speak on the phone or see each other regularly.

Sarah used to be part of a local amateur dramatics group, which she enjoyed a great deal because it was a good way of meeting people and made her feel like part of the community. Since her mobility has decreased, she has had to give this up.

### Planning care

Sarah went to see a GP who advised that she get in touch with a counsellor and enquire about getting help through Care Direct.

Sarah called Care Direct after moving out of her sister's house. They put her in touch with a social worker. The social worker arranged a care package for Sarah.

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*Wellbeing is a lot more than alleviating my disability. It's not just pain relief. It's more about thriving for me. If I'm feeling better than I'm more in control of what I eat, and I get out and walk. Getting the right factors in place is very important. It's a very personal thing as well.*

Sarah's thoughts on independence and wellbeing

## Being cared for

Sarah has carers provided by B&S care that visit her every morning. They help her to get dressed, to get her up and moving about, to clean her flat and to prepare food. Having a healthy diet is a very important part of Sarah's life, because it has a direct effect on how pronounced her MS is.

She finds that the carers are not very well informed about her condition and about how to make healthy food, and this bothers her. "You get the feeling some carers aren't in the profession to care. They have bad working conditions (pay, hours) and this filters down to the care you receive. I want someone who's on the same page as me and understands the things that are important to me."

Sarah also doesn't like it when the carers that visit her are inconsistent because she has to explain the nuances of her condition to them each time a new one comes, which she finds tiring. She doesn't like that many of the carers do not clean properly, and that often they are young. She would prefer someone of a similar age to her.

Being encouraged to get out of bed is very important to Sarah - sometimes the carers turn up so late she is still in bed in the afternoon. This has a knock on effect to her MS and sense of wellbeing.

Sarah visits the doctor's surgery from time to time but does not have a regular GP. During her stay in hospital she was assigned an MS consultant, and they provide ongoing advice.

Sarah goes to an MS treatment centre where she has oxygen therapy once a week. She likes that this provides her with a bit of a sense of community, but doesn't socialise with the other service users outside of the treatment centre because she doesn't want MS to become all that she is.

Sarah also has a brother - he lives on the other side of Bristol to Sarah, and although he would like to be able to help her more he is working hard and doesn't have much time to be able to visit.

Sarah would like to be able to visit her son from time to time, but she struggles with public transport and taxis are too expensive. Sarah has a friend who takes her to the theatre from time to time. Without her Sarah would find Bristol very difficult and she would be more lonely.

## Reviewing my care

Sarah requested a review of her care 5 months ago as she is not happy with the carers she has. She is still waiting for a review date.

She has heard about Direct Payments through a friend and thought it would be good to be able to employ someone that she likes. However she feels that it would be too complex for her to set up and keep going as she would have to become an employer and learn about employment law. "I don't understand why I have to go on a course about employment law so I can get a carer I want."



## Sarah, 60. Widowed.

Is new to the care system, living at home  
Proactive in care planning

### Re-write the story

#### Trigger

Sarah was diagnosed with MS 6 years ago. Before the illness, she was very independent and worked full time. She has since had to give up work. She has poor mobility a lot of the time and usually has to use a frame to walk.

#### Change in situation

Sarah's husband used to care for her, but he died 4 years ago.

#### Planning care

Before her husband died, Sarah's MS Consultant put her in touch with a Care Coordinator called Richard. Richard and Sarah discussed the future, and what would happen when her husband died. They discussed different housing options, and agreed that it would be best for Sarah to be in a flat on the ground floor that had a garden so that she could get fresh air and be in a calm outdoor environment. Richard got in touch with the housing team to ask them to contact Sarah. After their appointment, the housing team put Sarah on the waiting list for a council flat that ticked these boxes. Sarah and Richard also discussed Sarah's care needs for when her MS becomes more severe. Richard arranged for Sarah to speak to a Social Worker so that a plan could be put in place so that when this was needed, everything would be ready. During the assessment, the Social Worker also found out about what Sarah likes doing, and found ways that she could be supported to carry on with these things in the future, for example her amateur dramatics group.

Richard gave Sarah an iPad and set her up with training to use it. As part of this training Sarah was shown how to use a free app that she can track how her illness is progressing.

## Being cared for

When Sarah's husband died, Sarah phoned Richard to let him know. He told Sarah to phone Care Direct. They arranged for someone to visit her to talk through her care needs at the moment. Because she had been tracking how her illness was developing on the iPad app, she was able to show the assessor this rather than struggling to recall things, which can be tricky because her illness is very changeable. Care Direct put Sarah in touch with a brokerage service that helped her to find a consistent carer who is knowledgeable about MS and is interested in food and diet, which were the things that Sarah told them were important to her. They offered her the choice of helping her find a care agency that she liked, or helping her to set up Direct Payments. They agreed that Direct Payments would be the best option for her. The brokerage service set this up and contacted WECIL on her behalf so that she didn't need to worry about issues around employment law. At the moment her carer visits her for 45 minutes every morning and she enjoys their visits.

Sarah was given a budget through Direct Payments, and can use it to pay for the care that she needs. Sometimes this is more, sometimes this is less. This is because the severity of her MS can be very changeable. To keep track of how much of her budget she has spent, she logs the carer's time on an app on her iPad. The app is linked up to the care team. If she starts to consistently use a lot more care, this is automatically flagged to Richard, her Care Coordinator. He can then arrange for her Social Worker to arrange a review with her.

Sarah has a PIP (Personal Independence Payment) that she uses to pay for taxis so that she can get out and about and can continue with her amateur dramatics group. She enjoys being able to mix with different kinds of people and being able to continue with her interests and hobbies.



## Bill, 71. Single.

Long term care user in sheltered housing

Passive in care planning



*I'm not independent. The word independent makes me feel frightened.*

Bill's thoughts in independence and wellbeing

### How long have they been caring for



### How engaged with their care are they



### How vulnerable are they



### Independence before illness



### How much of a support network do they have



## Trigger

Bill is a service user with complex needs. He has been in and out of institutions since he was a child, and has been receiving care for all of his adult life. He has a personality disorder and a degree of cognitive impairment. In more recent years he has developed heart and respiratory problems, as well as having decreased mobility. He uses a frame to help him walk.

## Change in my situation

Bill used to live in a care home where carers were on call 24 hours, but following an incident he was moved out of there and into the sheltered accommodation. He isn't sure what happened. Often he has trouble recalling events.

Bill has a son who used to visit him regularly, however they fell out a few years ago and no longer see each other. Bill wishes that he had more people to talk to.

## Being cared for

Bill currently lives in sheltered accommodation on the outskirts of Bristol. He doesn't like it there because there aren't carers around to talk to throughout the day and his cat is not allowed to live with him. He feels very lonely and is scared of being on his own.

Bill has a carer that comes to visit him for half an hour in the morning and half an hour in the evening, 7 days a week. The carer helps him with his personal care and getting food ready. Sometimes he likes having the company, and other times he feels like it's too overwhelming having someone in his home and making him shower.

Bill sees his social worker regularly. Other than his social worker he doesn't know who he would get in touch with if he wanted to discuss his care or how he would do this.

Because of Bill's personality disorder, people can't always tell if he's telling the truth or not and he finds it hard to articulate what he wants or needs. This makes it hard when planning his care package. Bill is relatively new to his social worker's caseload, and they are still learning Bill's characteristic and how to read him.

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*Ongoing support that's what I need. I want support for the rest of my life.*

Bill's thoughts on BCC's future plans

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*I've never dealt with money. It was just given to me. Managing money myself would make me feel anxious. I'd just go to my social worker to help me.*

Bill's thoughts in independence and wellbeing

Bill used to go out twice a week with Second Step. Since moving to this new home this has decreased to once every other week. He doesn't know why this has happened. He now feels very isolated and doesn't feel that he is able to go out on his own instead. This is because he gets frightened and struggles with accessing places due to his limited mobility. "When I go out on my own I think Oh my God I'm on my own. I think it's fear. Fear of the unknown. It makes me anxious and frightened."

Bill likes to do puzzles at home, but other than this Bill has no interests or hobbies.

### Reviewing care

Bills social worker recently discussed the possibility of moving to a new home with more full time care where he could have his cat. He is not sure how he feels about this sometimes he thinks this could be a good idea and other times the thought of going somewhere new frightens him.



## Bill, 71. Single.

Long term care user in sheltered housing  
Passive in care planning

### Re-write the story

#### Trigger

Bill is a service user with complex needs. He has been in and out of institutions since he was a child, and has been receiving care for all of his adult life. He has a personality disorder and a degree of cognitive impairment. In more recent years he has developed heart and respiratory problems, as well as having decreased mobility. He uses a frame to help him walk.

#### Change in situation

6 months ago Bill moved to Extra Care housing, which his Social Worker Laura organised. He likes it here because he could bring his cat with him, and there are plenty of people to talk to around the building and grounds and in the café. He also likes that there are carers available all of the time. Laura had suggested the Extra Care housing as an option because he had often told her that he felt lonely and anxious when he was alone.

Bill has a son who used to visit him regularly, however they fell out a few years ago and no longer see each other. Bill feels sad that they are no longer in contact, but is grateful that he has plenty of other people to talk to.

#### Being cared for

Laura and Bill had spoken on many occasions about Bill's likes and dislikes in terms of carers. Laura liaised with care providers and managed to find a carer that was a good match for Bill. His carer visits for half an hour in the morning 7 days a week. The carer helps him with his personal care and getting food ready. Bill enjoys the visits and they have a good laugh.

Bill goes out with Second Step once a week. He really enjoys going out with other people and feels that his confidence has improved because of this.

The community psychiatric nurse visits Bill every other week for a chat. Bill likes knowing that he will have the opportunity to talk to her about his feelings and problems.

Laura sees Bill regularly and she knows his personality well. She has learnt how to work with Bill in a positive way, and is able to gain insight into his wishes and needs through asking indirect questions and observing his behaviour, because Bill is often unable to articulate what he feels. Laura worked with Bill to draw up a Person Centred Plan that shows what he likes and dislikes, things he's interested in, important people in his life, his medical needs and a bit about his history. Bill felt really proud of what they created, and likes to show it to other people. This also helps other people who don't know Bill so well to understand where he's coming from.

## Reviewing care

Laura recently discovered that Bill would like more company. She suggested to him that he try out the Shared Lives buddy scheme. She explained to him that this would involve someone from a family who were part of the Shared Lives scheme visiting Bill or going out with him once a week. Bill was keen on the idea and has been having visits from Martin every week.

A few months later Laura had a conversation with Bill about the idea of moving in with Martin and his family, or whether he would rather continue living in the Extra Care housing and having a carer visit him. He was informed by Laura that this would be paid for out of his personal budget, which would be managed by CoFS (Community Finance Support scheme). Bill really enjoyed the time he spent with Martin and likes having company. So he decided he'd like to move in with Martin's family, and is excited about it. Because he'd already spent time with Martin he didn't feel anxious about the idea of moving.



## Tom, 58. Married.

Has been using care at home for 2 years.  
Passive in care planning

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*The only bit of independence I have is being able to stand up now and again using my electric armchair.*

Tom's thoughts on independence and wellbeing

How long have they been caring for



How engaged with their care are they



How vulnerable are they



Independence before illness



How much of a support network do they have



### Trigger

Tom suffered a stroke a year ago and was hospitalised.

### Change in my situation

After 6 weeks in hospital he returned home to live with his wife, Joan (57), in the home they have shared for 25 years.

Since having the stroke he is unable to use his left arm and leg, and uses an electric wheelchair to get around.

Tom hated being in hospital. He wanted to “escape”. Although the staff were kind to him, on many occasions he was left “in a state” (incontinence) because they were too busy. He dreads going back there because “it’s always something bad that has happened that puts you there”. He feels very negative about the thought of going to hospital. During his stay there Tom was seen by consultants, physiotherapists, stroke nurses, and speech and food specialists. For some time he had a feeding tube which he hated. It was a relief when he could have it removed and could eat food again.

### Planning care

Tom and Joan both struggle to remember much about what happened around the time of his stroke because it was overwhelming for them both. Tom described this as “feeling fuzzy”. They know that Tom has a care plan, but are not sure where it came from and how it was arranged.

### Being cared for

Joan cares for Tom, which can be exhausting for her at times. Tom feels bad that Joan has to do so much for him, and wishes he was able to do the things that he used to do and to get out more. Joan has been shown how to do the physiotherapy exercises with Tom and was told to do them with Tom, but she does not have the strength to help with them. No one visits him to help with this. Tom and Joan feel that Tom has been left with no support in terms of his rehabilitation because he is over 55. Tom has dreams of being able to walk again, and feels sad when he wakes up from these dreams. However he has no motivation to work towards walking again, and is concerned about “bothering” people to help him do this. “I’d like to do more for myself but when it goes wrong people have to come and help me and I don’t want to be a burden.”

“

*Independence would be walking again but that's not going to happen. I'd like to do more for myself but I don't want to put people out when it goes wrong.*

Tom's thoughts on independence and wellbeing

“

*I'm anxious about what the new company will be like. I've had ones which have frightened me. They're clumsy. It scares me.*

Tom's thoughts on changing care providers

Tom and Joan have a disabled car parking space outside their house which can make life a little easier for them. However their neighbours often park in it which means that they have to find a parking space far away from the house. When this happens, going out turns into even more of a struggle. They have a blue badge but this can often be difficult to get. Last time Joan applied for a new badge she had to wait 10 weeks which was quite frustrating. Once it arrived they could only use it for 2 weeks before it ran out.

Tom would like to be able to get out and about in his electric wheelchair more often to go to the shops or to a cafe but there are often accessibility issues which prevent him from doing this. There is also a cobbled section of pavement on the road they live on, which means that he has to go onto the road to get past this section which can be difficult. Joan has complained to the council on many occasions but nothing has come of it. She feels that she doesn't have the energy to continue complaining about it. "If I can get out in my chair by myself it's a great help. But the pavements on my road prevent me from doing this. We've told the council but they do nothing."

Tom currently has a carer come to visit him every morning for 45 minutes to help with his personal care. Tom has issues with people he doesn't know attending to his personal care needs due to an incident that happened in his past. Because of this he finds it upsetting when new carers start visiting him. Joan often ends up doing a lot of the caring herself instead. Tom is not happy with the current care provider, but does not know if he can change providers or not. Joan has complained directly to the care provider about the care Tom has received but since then the carers have been arriving up to 2 hours late. Joan feels that the care provider are targeting them because she complained and is therefore reluctant to complain again. "There's no one else to complain to."

Both Tom and Joan like being at home. They don't have any interests other than watching television. They aren't sociable but if Joan is ill, sometimes their neighbour will go to the shops for her and sit with Tom. They don't have any family.

### Reviewing care

They recently received a letter about a change in their care provider in the future to be provided by a 'local' care company. They are waiting for news of this care company and change to their care plan and hope that they will be better than the current providers but anxious in case they are worse.

"I don't feel that I can trust new carers. I have to supervise them. I'm worried they'll drop Tom. You never know what level of care you're going to get."



## Tom, 58. Married.

Has been using care at home for 2 years.

Passive in care planning

### Re-write the story

#### Trigger

Tom suffered a stroke a year ago and was hospitalised. During his stay there Tom was seen by consultants, physiotherapists, stroke nurses, and speech and food specialists.

#### Change in situation

After 6 weeks in hospital he returned home to live with his wife, Joan (57), in the home they have shared for 25 years.

Since having the stroke he is unable to use his left arm and leg, and uses an electric wheelchair to get around.

#### Planning care

Before Tom was discharged from hospital, a meeting was arranged with the hospital discharge team for Tom and Joan to discuss their needs for when Tom returned home. They were also introduced to Mark, the Care Coordinator that had been assigned to them. The hospital discharge team explained to Jane and her parents that a Care Coordinator is someone who helps people to navigate the care system and will be able to put them in touch with the right people at the right time. At the meeting, Mark and Tom discussed what Tom felt was important to him in a carer. Mark discovered that Tom would like female carers that were over 40, and to have 3 or 4 carers that remained consistent. Tom also said that he'd like to know which carer was coming in advance. Mark took note of all of this.

Joan felt that she was out of her depth in terms of finding a carer that Tom would be happy with, so Mark put them in touch with a brokerage service that could help them find carers that Tom liked. Mark passed on the notes to the brokerage service so that they knew what was important to Tom in a carer. The brokerage service told Tom and Joan that they could choose between setting up Direct Payments or choosing a gold star care provider that they could read the ratings for (both public reviews and official reviews). They explained to them that WECIL could take care of the tax etc if they chose to set up Direct Payments. Tom and Joan decided to give Direct Payments a go.

Mark referred Tom to the stroke support team and requested that they get in touch with Tom. A stroke support worker now visits Tom every fortnight to see how he's getting on and to offer support as he goes through the different stages of stroke recovery. This was a relief to both Tom and Joan because they felt like they had an expert who would be able to guide them through the journey.

## Being cared for

Tom currently has a carer come to visit him every morning for 45 minutes to help with his personal care. Tom likes the carers that he's been matched with and feels that he can trust them. He knows that if ever he wasn't happy with the care he was receiving, he could tell Mark and Mark would point them in the right direction so that they can improve the situation.

Mark is able to think about all the services that Tom would need, for example physiotherapists, occupational therapists, the stroke support worker and getting their blue badge from the Council. He got in touch with these services and asked them to contact Tom to set these things up. He is also able to refer Joan to have respite when she needs it. Joan feels that she has enough energy to support Tom emotionally and to maintain their home. Joan visits a stroke support group for carers every fortnight, which she finds helpful. She is able to use her carer's allowance to pay for a sitter when she goes to the group.

Mark has got to know Tom well over the last year and they have established a relationship of trust. Mark is good at finding out what Tom needs and is able to suggest things for him to try in a way that appeals to Tom. For example telling Tom about the trips out that the Stroke Club organise.

Mark and Tom are working together to find different things to try to help rehabilitate Tom so that he can become more independent. Not having to rely so much on Joan and his carers means a lot to Tom, and he feels positive about the future. A physiotherapist visits Tom once a week and Tom is seeing improvements each time.

Tom likes to get out and about in his electric wheelchair to go to the shops or to a cafe but there is a cobbled section of pavement on the road they live on. This means that he has to go onto the road to get past this section which can be difficult. Joan asked Mark to find out if the Council would pave over this. Mark explained to her and Tom that this would not be possible because the cobbles are listed. Instead Mark suggested they apply for funding for a mobility scooter and put them in touch with WECIL who can help them with this. He also suggested that it might be worth considering moving home now or at some point in the future to a more accessible house.

Mark put Tom in touch with a volunteer called Sam from RVS (Royal Voluntary Service) who visits Tom once a week. Through these regular visits Tom feels like he has more of a link with the community, and it helps to take some of the pressure off of Joan.

Mark and Tom have discussed the idea of Tom getting a part time job in the future, perhaps at a charity shop. Tom likes the idea of having a goal to work towards, and he likes the idea of regaining a sense of purpose.