- My care at home -
People's experiences of home care in Suffolk

Executive Summary
‘It’s a personal thing, isn’t it? And you’re allowing somebody into your own personal house, your own space, to do a personal thing. And I think it’s important to have that rapport, whereas, if it continually changes, it’s like, a stranger suddenly come to do a personal thing.’

A home care service user
Healthwatch Suffolk can only instigate change and improve the experience of health and social care in Suffolk if local people in Suffolk continue to take the time to share their views with us. We would therefore like to acknowledge and extend our gratitude to every person who responded to our survey and participated in our interviews. We give special thanks to those who agreed to be case studies.

We would also like to thank staff at Suffolk County Council, the Care Quality Commission (CQC) and ACE Anglia for their support in facilitating this research.
Suffolk County Council (SCC) is committed to ensuring that the delivery of care for the future is sustainable, affordable and meets peoples’ individual needs.

In Suffolk we are facing significant challenges as the population of older people (65+ years), is predicted to increase by nearly 50% in the next 20 years from more than 173,000 to over 255,000. In addition, there are approximately 13,000 people living with dementia in Suffolk at present and this is also forecast to almost double to over 24,000. Most new cases are predicted to be in people aged 85+ years, who are also very likely to have care needs.

SCC contracts with over 80 home care providers that delivered almost 2 million care hours to 5,585 customers in 2016/17. We are very pleased that for almost 80% of the respondents they are satisfied with the quality of the care they receive. A much smaller number of people, 50, have then provided a more detailed response that has resulted in a number of recommendations.

SCC will take time to carefully consider and provide a detailed response to the recommendations including how they will be used to inform our plans for the future. For information, we have agreed with our providers and key stakeholders a set of Home Care Principles that we are striving to achieve; listed below:

1. Reliable Provision of safe care is the overriding priority.
2. To ensure guaranteed good quality and reliable care for customers at all times and across all areas.
3. Solutions that work for and across the whole care system and support Supporting Lives Connecting Communities and the Care Act.
4. Affordable and sustainable outcome-focused care and support in the long term with a focus on reducing demand through an enabling approach

5. Solutions that are flexible and can accommodate more complex customer needs that allow them to remain independent for as long as possible

I would like to share my heartfelt thanks to everyone who participated in the survey and Healthwatch Suffolk for completing this valuable research.

“Suffolk County Council will take time to carefully consider and provide a detailed response to the recommendations including how they will be used to inform our plans for the future.”

*Mike Hennessey*
EXECUTIVE SUMMARY

‘My Care at Home’, research carried out by Healthwatch Suffolk (HWS) and commissioned by Suffolk County Council (SCC), provides an overview of service user and family carer experience of home care services in Suffolk. Research into such services is extremely important in the context of an ageing population, finite funding of social care in the midst of national austerity measures, and findings from other local Healthwatch that suggest the experience of service users is largely the same across the country.1

As a result of information received from local stakeholders and service users in Suffolk, HWS designed this project to discover what local service users and their family carers think of their home care service. The themes and recommendations of this report, many of which reflect mostly smaller scale studies conducted by ten other local Healthwatch, seek to highlight opportunities for bringing about a wide range of changes that could collectively add to the current quality of home care provision in Suffolk.

The project was designed in two phases and started in November 2017. Healthwatch Suffolk recognises that conducting such a survey during a winter period, and in particular a winter that had a distinct impact on rural health and care systems nationally, could be reflected in some of the survey and interview responses.

Service users and their family members were initially contacted through a scoping survey, which was mainly distributed by SCC to a random selection of 2,164 service users of Council funded care. Scoping surveys were also distributed by voluntary sector services and Healthwatch Suffolk’s Community Development Team. The scoping surveys gave service users an opportunity to give a satisfaction rating and asked for respondents to share some details about their experience of care. Surveys were received from 517 service users, family members and friends, involving 76 different care providers, including both private providers and Council funded care services. Nine responses were received from professionals which were not included in the analysis due to the low response rate. There was generally high satisfaction with the care received. Underlying problems were often highlighted in the open-ended question responses.

Phase two of the research consisted of 50 in-depth qualitative semi-structured interviews involving 72 service users and/or their family members. These explored service user’s experience of care in more detail. Every effort was made to interview service users from different localities and involving a wide range of care providers.

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1 The end of formal adult Social Care – a Provocation International Longevity Centre December 2015 www.ilcuk.org.uk
Briefing paper Number CBP07903: Adult Social Care Funding (England); 19 April 2018 pp 8-13 https://researchbriefings.parliament.uk/ResearchBriefing/Summary/
Healthwatch Briefing: Home Care: What people told Healthwatch about their experiences; August 2017 pp17 https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20170702_home_care_.what_people_toldLocal_healthwatch.pdf
To make it worse, I’m a barcode now. I’ve become a barcode and I get scanned in the mornings...

Home care service user
<table>
<thead>
<tr>
<th>Provider</th>
<th>Number of Responses</th>
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<td>East of England</td>
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Number of responses from each provider.
Findings from both the surveys and interviews were analysed thematically, drawing on Healthwatch England (HWE) and NICE guidelines about what good home care should look like. Although the main themes in both the surveys and interviews were found to be comparable to the five criteria that define 'good care', other issues not included in the guidelines such as timekeeping and communication were also important to service users.

Further issues that arose from the research are detailed on page 16.

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RESULTS

The following nine sub-themes identified through the research are presented in order of importance in the scoping survey. These sub-themes include information from the interviews, in the process offering a more detailed picture of home care service user’s experiences.

The recommendations from this report are intended to inform care providers and Suffolk County Council in order to enable them to build upon current strengths, such as the consistently good quality interaction between service users, family members and their carers, and also to address current weaknesses in home care in Suffolk from the perspective of the service user. Healthwatch Suffolk recommendations are not universally reflected by what service users and family members have said. The breadth and depth of feeling and observations expressed by service users and at times their family members, varies from one recommendation to another. The intentions of the 15 recommendations lie in the premise that an ambition to address them, collectively, would lead to a more rounded, more consistent and more efficient local service and improved outcomes for the service user.

1. Carers treat the service user with dignity and respect.

Service user’s and family member’s comments often referred to having carers who treated them with dignity, kindness, politeness and with a caring attitude. There were 70 positive comments from the survey and 34 from the interviews about being treated with dignity and respect. Only four negative comments were made in the survey, and four in the interviews.

“The main carers. They’re brilliant…. And they can’t do enough to be gentle with me, to do things really kindly. I have a laugh with them, you hear us laughing up there and we have a lovely time where we do it. And I think that makes a difference.”

2. Carers are helpful

Many service users told HWS that their carers act in a compassionate and helpful manner. There were 60 positive comments in the survey about carers being helpful and 23 in the interviews. Three survey respondents made negative comments and five in the interviews. Related to the issue of helpfulness is carers having time to complete all the tasks necessary to meet the service users needs. Lack of organisation and poor timekeeping can impact on carers ability to complete tasks.

“My support staff are very helpful. They help me with all aspects of my life, mail, personal prompts, social, prompts to do laundry, cleaning, check the food is in date etc medication checks.”
3. Carers engage with the service user

A number of service users told HWS how important it was to them to have a carer who talks to them and is sociable and friendly. Fifty eight survey respondents and twenty six interviews made positive references to carers engaging with them. There were only two negative survey comments and 10 negative interview references.

I think he's happy. I think he likes it [when the carers come], and the interaction for him for somebody else is so good. It might be the only person he speaks to the whole day or for several days other than me. You see?

58 respondents said that engaging with their carers was important to them.

4. The carers are not usually on time

Carers arriving late was frequently raised in both the survey and interviews. This could often cause distress and anxiety for the service user. Forty six survey respondents and 30 interviewees made negative references to their carer’s timekeeping. Twenty one survey respondents and eight of the interviews made positive references. In 20 interviews participants also told us that they sympathised with their carers, even if they were late.

It's not their fault if they're late sometimes because they never know what they're going into. And I understand all that.

5. Service user is not visited at their preferred timings

Carers arriving at inconvenient or inappropriate times for the service user can lead to disruption to normal daily routines. This was sometimes felt to be a result of poor management. There were 29 negative comments about inappropriate visit timings in the survey and 23 in the interviews.

Timings of visits not always appropriate [e.g.] arriving at 3pm to prepare my mother’s tea, arriving early for bedtime

6. Consistent care is not provided

Service users told HWS that they appreciated seeing the same carer regularly, in order to build a relationship and to be cared for by someone who understood them and knew their needs. Twenty eight survey respondents and 18 interviewees
made negative comments about the consistency of their carers. There were 10 positive survey comments and 21 positive interview comments. Survey respondents and interviewees who made negative comments often related inconsistent care to management or care agencies not having enough staff.

**Carers are good. Office is not.** They struggle with shortage of carers. When our regular carer has days off, cover is chancy.

7. **Service user is not told if the carers are going to be late or not arrive**

Related to timekeeping is the issue of not informing the service user if the carers are going to be late or not arrive. Often service users understand changes to timings of visits if they are notified in advance. Not being notified of changes can cause disruption and distress, therefore having an accurate rota which is adhered to is valuable to the service user. There were five positive references to being notified of changes in the survey and 26 in the interviews. 24 negative survey comments were made and 18 interviews contained negative references.

"I mean, I sit here waiting for a carer and the carer doesn’t arrive. So after half an hour or so I ring up and I say, ‘What’s happened? Where’s my care? ‘Oh, he’s had to do such and such. But we’ll get there as soon as we can.’ But they should have notified us I can’t see why they can’t phone me and just say, ‘your carer is going to be half an hour late.’"

The themes of timekeeping and communication came up with the majority of respondents feeling negative about these. Timekeeping with the biggest negative theme.

8. **Carers do not always arrive**

Both survey responses and the interviews contained references to carers sometimes not arriving at all. This has led in some cases to situations which fell far below the standard expected of good care. 23 survey respondents told HWS that there were occasions when no carers arrived to provide their care at all and this was also raised in 10 of the interviews. Reasons given for non-arrival included travel times, care agencies not having enough staff and unexpected events occurring elsewhere.
Occasionally no carer has turned up, this is particularly of a concern on the first and last visits (out of the four a day) when it involves getting up and putting to bed which cannot be done independently. This had resulted in emergency cord having to be pulled.

Not having consistent carers was highlighted as one of the sub-themes of most concern to participants.

No consistency of care as too many changes of staff on a daily basis, despite being with this company for 4 years... [The client] is in constant pain if handled incorrectly by carers, despite being shown or told on several occasions.

9. Carers do not know the service user’s needs

Carers knowing the service user’s needs has been interpreted as knowing the contents of the care plan and the service users likes and dislikes. There were 17 positive references to carers knowing the service user’s needs in the survey, and 31 interviews made positive comments. Twenty one survey respondents made negative comments and 19 interviews made negative references. Not knowing the service user’s needs was often linked with consistency of carers, and several interviewees (12) told HWS that they felt that their main carer(s) know their needs but that replacement carers have little knowledge of the care plan or are not informed enough about their likes or dislikes.
OTHER ISSUES RAISED IN THE RESEARCH INCLUDE:

**Communication**

A number of issues arose in both the surveys and the interviews around service users having difficulty in communicating with the care agency office. This includes:

- providers not responding to service user's complaints or queries in a satisfactory way;
- the office not being easy to contact; and
- care agency office staff communicating politely and with respect with the service user.

Thirty two of the 517 respondents to the scoping survey made negative comments about these topics and 23 interviews contained negative references. Twelve survey respondents made positive comments within this theme and 24 were made in the interviews. This suggests that some care providers do resolve issues to the satisfaction of the service user.

**Care plans and diaries**

The documentation that relates to the delivery of home care e.g care plans and care diaries did not feature greatly in the surveys. They were however, discussed at interview. There was often some confusion about what the documentation was and where it could be found in the service user’s folder. The HWS researchers also sometimes had difficulty in finding the relevant documents. Only five service users in the 50 interviews said that they did not have a care plan, but eight service users or family members were not sure what was in it. Care plans are very useful to both the service user and carer and give certainty to the needs of the service user.

**Training**

Comments about training related to the operation of medical equipment, manual handling and daily living aids, as well as basic food hygiene, infection control and knowing the service user’s health conditions and needs. In the survey six made positive comments about their carers training and 10 made negative comments. In contrast, out of 50 interviews, 20 made negative comments about their carers training and seven made positive comments.

“*I'm expected to sit up, which is very hard, but they haven't read my medical records so they don't really know how to deal with me. I wish they could be properly trained, these people because I'm a serious medical condition after all that's happened to me. And they're not complying with this at all.*”

**No but that's how you feel. I'm afraid now. I very rarely ring up. It's only if I need something changed or I want to cancel something, I ring them up. Because otherwise, it's not worth it.**
user. Not all those interviewed spoke about care diaries, but 26 service users or family members from the interviews confirmed diaries were completed. Some problems could be caused when invoicing for the care delivered when diaries were not checked or accurate.

“We are pleased with the care received to date, carers are respectful and arrive on time, all care plans have been discussed and the company have listened and worked well to put in place the care needed working with the occupational therapist to get it right for my partner.”

22 service users said they felt they were involved in developing their care plan.

“They are very reliable and professional. The new ones are always taught well to do their job.”

Home care service user
Changing provider

In the interview, service users were asked about their experience of changing provider. Only 8 survey responses out of 517 referred to this topic. However, 31 of the 50 interviewees discussed changing providers. One of the most important issues raised within this theme was that in 17 of the interviews, participants said that they had no choice of provider on either discharge from hospital or if a care provider ceases to provide care.

Suffolk County Council

A number of comments also arose in the research about Suffolk County Council’s involvement in the procurement, management and funding of care. The most important common issue for service users in relation to SCC was invoicing. There were 8 negative comments about SCC invoicing in the survey and 11 in the interviews. These included service users being sent invoices in error, or service users or family members stating SCC may have been invoiced for care they had not received.

Travel distances

Issues relating to timekeeping, consistency of carers and completing tasks to a high standard, were raised by service users. They were often perceived to be because carers were not given enough time for travel between appointments and long travel distances. This was often related to poor organisational skills or lack of local knowledge by the care agency office.

Career path

Service users often sympathised with their carers and made comments about their carers’ demanding workload, low pay and low job status. This was related by service users to comments about timekeeping, consistency and non-arrival through care agencies having too few carers and a high turnover of staff, as a result of a low regard for caring as a career.

“My main problem is SCC who invoice for my mother in laws care. The invoices are NEVER correct and they always overcharge. I am presently in dispute with them. I would like to discuss this with you...”

“. the care agency and the office staff do not appreciate some of the carers and I don’t think society does. Just like waitresses. No, I don’t think people look at it as a career. It’s like, “Oh, you’re just a carer.” Well, to me, carers should be shown a bit more respect because they have to do all these personal things, etc. There’s a lot more to it, and I don’t think the care agency really respects the staff enough, you know?”
CONCLUSION

This research into home care was wide-ranging and the results and recommendations highlight the strengths and weaknesses in the home care system as experienced by the service user. Where consistent care is provided, and service users know their carers well and are treated with dignity and respect, they feel real benefit. Lateness, non-arrival and having too many different carers can cause distress and confusion. Good communication and co-operation between service user and care provider gives confidence and stability to the service user and their families. Consistent training in all areas of care also benefits the service user. In a rural county like Suffolk, the difficulties in providing care to all communities are self-evident. HWS believes that acting on the 15 recommendations set out in this report can build on the aspects of home care which are already satisfactory and address shortcomings for the benefit of all those concerned.

Recommendations

1. Knowing the service user’s needs

Replacement carers should have access to a record of service user needs, likes and dislikes and take note before caring for the individual.

2. Being treated with dignity and respect

Providers should ensure that carers are aware of what it means to be treated with dignity and respect.

3. Helpfulness and time to care

Care providers need to ensure that carers are given time to meet service user’s needs and to carry out the tasks required.

4. Engaging with the service user

Care providers should always aim to make carers aware of the importance of talking and listening to the service user. Carers need to recognize that they are in the service user’s home and treat them with kindness and consideration, taking into account their spiritual, social and cultural needs.

5. Consistent carers provided

Care agencies should aim to guarantee that their staff/service user ratio is sufficient to ensure that a service user can rely on a specific carer or group of carers on a regular basis.

6. Carer’s travel distances

Care agencies should ensure that the travel distances between appointments are realistic.

7. Notifying the service user of changes

Service users should have ready access to an accurate rota. If any changes occur to the carer attending, or the time of arrival, the service user should be notified at the earliest opportunity.
8. **Training**

Suffolk County Council and care providers should aim to ensure that training for carers meets statutory and regulatory requirements and be consistent across providers. The training should be aimed at meeting the needs of service users and comply with manual handling and health and safety requirements. Carers should also receive appropriate training in food preparation, hygiene and infection control.

9. **Preferred times**

Care providers should, where possible, offer service users their preferred timings and when this is not possible, notify them at the earliest opportunity.

10. **Care plan, care diary and personal information**

Personal care plans should be co-produced with the service user and reviewed every six months. Care plans need to be printed in an accessible manner and stored in a clearly marked folder. The folder should also contain a copy of the care diary and this should be correctly completed.

11. **Carers not arriving at all**

The care provider should aim to inform the service user, at the earliest opportunity, if a problem with keeping to an appointment arises and replacement carers are sent.

12. **Contacting the care agency**

Service users would benefit from having contact numbers and names, which should be displayed prominently in the care folder. A commitment to answering calls should be made by the provider for the hours that the contract specifies.

13. **Changing Providers**

Where possible service users should be given choice of provider and if change has to be imposed for any reason the service user should be kept informed and reassured during the process.

14. **Caring as a career**

Carers should be encouraged to undertake accredited training and achieve recognised qualifications which could raise the public perception of caring as a career.

15. **Suffolk County Council invoicing**

The processes and procedures of Suffolk County Council home care service invoicing could be improved to prevent inaccuracies and lateness.
Janet’s story...

- It gives me time to lead my own life. To take the dogs for a walk or walk my grandson to school. A little normality in a day that can be exhausting. I know my husband is cared for.

Janet is the main carer for her husband who suffered brain damage following a fall in 2011. He has since been mostly bed ridden and in need of 24 hour care.

Up until last year the care they received was excellent but unfortunately, due to staff changes in both carers and managers, the care has been disrupted. It is now causing Janet some concern.

Janet has received invoices from her care provider, which is unusual and is becoming increasingly concerned because some of them are very old. She is also confused about the different methods available to her for managing the payments she receives for her husband’s care.

In addition to managing payments, her husband’s carer has also changed. He had the same carer for six years and they were happy that the carer understood his needs.

She understands my needs, and she uses her initiative and she helps support both of us really. She’s never late. She acts like a PA for me as well. She will sort out things that have to happen, like my husband having his haircut. She makes sure it is all arranged... I can walk out of my house and I just feel that everything is under control. I feel happy that she is there.

Unfortunately, due to changes in management, the time they have with this carer has been reduced. Janet feels they must now start again to

Having carers she could trust means Janet could find time to walk Oscar, which is important for her wellbeing.
build a relationship of trust with other carers, which is hard. She is also worried about whether the company has the capacity to provide properly trained carers.

Her husband can be demanding because of his brain damage. Having carers he likes and that they can trust is core to their experience being positive but Janet feels the changes to staff are undermining this and causing them stress.

Janet is positive about the carers. If her husband is asleep, they are willing to help with other household tasks. If he is awake, the carers will sit and engage with him.

The carers are understanding of how the changes in staff cover are affecting the couple. They do everything they can to ‘keep the package going’ by talking to each other and ensuring that cover is available.

“I can’t fault the individual carers that come out ... but they are struggling.”

Janet is worried about the future of her husband’s care and also about the respite she receives because of issues with funding. She is hoping that things will improve as the care and the office used to be so good.

She cannot fault her carers and considers the care agencies office and council systems to be the cause of her stress and uncertainty.
Edward’s care...

It gives my husband his dignity and some companionship. For me, it provides me with some time to myself, whilst knowing he is safe.

Edward is 80. He was an engineer and has developed complex health issues including Ataxia, Osteoporosis, Epilepsy and Coeliac Disease. He is now also developing Dementia and is suffering from mild depression. His deteriorating neurological condition affects his mobility.

He and his wife have lived in their home for over 30 years. They receive one carer in the morning, four days a week for half an hour and for three-quarters of an hour on three days a week. They describe their carers as “very pleasant” and “reliable”.

During the initial assessment of their needs, the couple felt there were too many people involved. Furthermore, despite these meetings, there were discrepancies between the care plan they received and the copy held by the provider. However, they said most of the carers knew what they had to do when they arrived and, those who didn’t, always read their care plan.

Edward and his wife were occasionally disappointed because, although they received a rota, they were not notified of any changes or contacted if carers were going to be late. Lateness was a problem, especially at weekends, when Edward could be waiting until 11am to be dressed.

Despite these issues, they knew all of their carers and Edward has always been satisfied with his care, even if they were seeing up to five different people in any given week.

‘There was overkill in that one day I had three people in my breakfast room, sitting there having coffee …. I felt that was total duplication having given the first member of staff all the information to write up the care plans ...’
After a call to the manager of the care agency about the problems they were having, things have got better. Carers now arrive on time and are always known to them. Edward is now getting “superb care”. He is able to get to his weekly art class on time due to the carers’ efficiency. He enjoys this class enormously and produces some very good artwork. His wife can find time to meet with friends and she often dashes out while the carer is present.

Edward has complex health issues but the efficiency and support of his carers means he can get to his weekly art class.

“...the carers are all very cheerful, have a good attitude and do everything asked of them.”

I think he’s happy... and the interaction for him with somebody else is good. It might be the only person other than me he speaks to for several days.

Edward is now getting “superb care”. He is able to get to his weekly art class on time due to the carers’ efficiency. He enjoys this class enormously and produces some very good artwork. His wife can find time to meet with friends and she often dashes out while the carer is present.

“...the carers are all very cheerful, have a good attitude and do everything asked of them.”
Gill’s care...

The most important thing to me is the day care they receive because they are stimulated. They do two different activities each day like sailing and swimming. They can do so many different things that stimulate them at the day centre.

Gill is a widow caring for two sons with learning difficulties and a brother of 76, also with learning difficulties, who has a flat within a supported living complex.

Her brother lived at home with his parents until they died, when Paula took over his care. He lived in a bungalow at the bottom of her garden. After the death of her husband, she found looking after all three of them too difficult and so she arranged for her brother to move into supported living.

Gill is still the main carer for her two sons, both of whom live at home and receive day care.

She feels that one of the providers is not satisfactory because they are not stimulating her son as much as she feels he needs. She is hoping to transfer him to the day centre that her other son attends and where they do something different every day. He loves it.

The family are still grieving for her husband and she is finding the situation difficult. She says “I have got to get through it for the boys”. She is grateful for her good neighbours and the care her family receive.

She did try respite but her son was distressed because he thought she might also disappear. She therefore needed to cancel it. However, she is considering contacting Suffolk Family Carers to see how they can help.

Gill does manage to find some time for herself during the day and her little dog is great company.

Her brother is happy with his new living arrangements and Paula feels they are “really kind, caring people”. When asked after a week whether he wanted to go back to the bungalow he said no. She visits him every week and checks that everything is going well.

His carers visit his flat to make his breakfast and his tea. Although they check on him just before he goes to bed he doesn’t have to go at any particular time.
Gill has always felt included in discussions about his care and everything is written down in a book. Although obviously being a carer for three adults is difficult, she is an active and sociable person who cares deeply for her family.

They support him with a shower and help with the clothes he is going to wear. He has lunch in the canteen with everyone else. They just look after him generally.

Gill feels that the stimulating activities provided by the day care centre her son attends (e.g. sailing and bowling) are important to the wellbeing of the family.
The most important thing is that I have not got to worry. Whatever happens, I know there will be someone to get me up in the morning whereas, if my partner is ill, we have to worry about finding someone else to come in to support me during the day.

Karen lives with her partner in a house designed for living with a disability. She has MS but is determined to live as independently as possible. She works tirelessly to ensure that her physical and mental mobility remain as good as she can possibly achieve. Through working with Suffolk County Council, she believes she has achieved this.

“...one of my things that I first said to them was I wanted to feel like I was running my home. I wanted to decide. I can't always do it. I can't do the dinner, but I can plan them out... I can have everything in place, and there's a meal on the table at 6 o'clock. I might not have done it, but I've organised it all. And that was important to me.”

Karen receives a personal budget from Suffolk County Council which she controls. It means she can arrange the care she needs herself.

She has had care since retiring from work on medical grounds seven to eight years ago. Her present carer has been with her for over three years. Her care plan has been increased gradually and she now has carers twice a day as well as other support during the day.

“They get me up at 07.30 - 08.00, and then I have somebody come in at 9:30am till 3:00pm. And then my partner comes home and that time varies. I can't set the times, but they've (the carers) got specific hours.”

The evening carers prepare her for bed around 9pm and prepare breakfast before they leave. Both she and her partner trust and rely on the carers and he often contacts the carers, or they him, to clarify what has happened at, for example, a doctors appointment because Karen is apt to forget.

She has always found Suffolk County Council responsive.
“I have to say, they’ve always listened. They’d go into my lifestyle, and one of the things in the early days was, “You need to get out. You’ve got to have somebody to get you out for your well-being, even if it’s only for a cup of coffee. What do you like to do?”

Karen feels the first provider she had was ‘not fit for purpose’ and she then transferred to her present provider who is local. Her life is busy and remaining involved is enormously important to her.

“Oh yes. Oh yes, I’ve got loads to be doing. I’m always active. The telly never goes on until 5 o’clock at night. And we’re always doing, aren’t we? We’ve always got some little project that I want to attack.”

So, with the support of her partner, her carers and her friends Karen maintains an active and interesting lifestyle despite her limited physical mobility. She is highly motivated, organized and determined to live life to the full.

‘...And that’s what I’m grateful for. Having that personal allowance and working closely with Suffolk County Council, I can run the house with the people that I get on with. They’re not people that are being told, ‘Just go in and sort her out.’ Because you might not get on with those sorts of people...so there’s that trust’.

Her carers always know what Karen wants to do and they can make it happen even if she can’t and as she says ‘there is a real rapport between us’.

Remaining as independent as possible is hugely important to Karen, who has MS. She feels in control of her life and her household because her care is arranged to account for her needs and wishes.
This report will be publicly available on the Healthwatch Suffolk website. It will also be made available to Suffolk County Council, which is responsible for the commissioning of home care services in Suffolk.

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