



Healthwatch Kent - March 2018

Focus on Hidden Carers.

What is it really like to be a carer?



Foreword

It is estimated that 1 in 9 adults living in Kent are caring for someone. That might be an elderly parent, a child, a spouse or even a neighbour. That's 151,000 people in Kent but that number could be much higher.

Kent County Council are currently reviewing the services that they provide for Carers in Kent. There are 5 Carers Support organisations in Kent who provide invaluable help and support to Carers but we know that not everyone is in touch with these agencies for a variety of reasons. Some people don't consider themselves to be Carers or don't realise that support is available to them. To support the review, we worked with Kent County Council to reach out to these hidden carers to ensure their voice was heard and used as part of the review.

We spoke to 158 Carers from all across Kent about their experiences and the challenges they face on a daily basis. Everything we have heard is in this report.

Normally we would make formal recommendations based on the feedback we have heard. In this report we have decided to purely share the feedback and ensure as many organisations as possible hear the voice of these hidden carers.

We have shared our findings with Kent County Council to use during the review of Carer services in Kent. A huge thank you to everyone who stopped and spoke to us. We heard some incredible stories. By sharing your experience with us, you have helped to improve the service for the future. We also wanted to thank the supermarkets who gave us permission to come and talk to their customers. Your help really has made a difference.

Do tell us your thoughts and share your own experiences with us. Contact us anytime for free on **0808 801 0102** or email **info@healthwatchkent.co.uk**

Steve Inett

Chief Executive, Healthwatch Kent



What were we trying to achieve?

We wanted to reach hidden carers across Kent who aren't part of official carer support groups. We wanted to hear from them directly about the experiences and challenges that they face.

How did we go about it?

We visited six supermarkets across Kent spending time in the entrance ways talking to members of the public.

We visited the following locations:

- Margate Tesco
- Dartford Sainsburys
- Tunbridge Wells Sainsburys
- New Romney Sainsburys
- Tenterden Tesco
- Sheerness Tesco

Thank you to all the stores who made it possible for us to talk to their customers.





What did we find? What did we see?



In Summary

- **50%** of the Carers we spoke to were caring for someone **over 50 hours a week**. Many people simply said 'they need looking after all the time'.
- The biggest challenge carers faced was their **psychological wellbeing**.
- This was closely followed by the need to manage nursing tasks and having **no time to get everything done**.
- **Extreme tiredness and feeling lonely** and isolated were also big issues for Carers.
- Most people we spoke to had either retired or been **forced to give up work** so that they could provide the care.



What did we find? What did we see? Continued

“I am so tired, the care is constant and physical”

“I don’t have anyone to share your fears and worries with, I am at breaking point”

“It’s a physical challenges to lift and move him on my own”

“It’s hard to manage my husband’s panics and fears”

“What happens when I ‘pop off’”

“I have lost all my friends”

“I don’t have anyone to share your fears and worries with, I am at breaking point”

“It’s a constant challenge”

“It’s hard to get to the Carers groups”

“So hard to manage her pain”

“My assessment didn’t match the reality of my life. They said I didn’t need support and made me sign it”

“I am desperately unhappy and angry”



What did we find? What did we see? Continued

“I am so exhausted all the time”

“Just a bit of time for myself, my health is not great either”

“I try to smile but it is hard”

“He is asleep now, that gives me about 25 minutes to dash to the shop before he wakes”

“I can’t be at home with my children as I need to be here with my parents”

“I watch him struggle daily and I can’t take that away”

“When he falls I can’t pick him up, I have to ask the neighbours for help”

“We had to take loan out to pay for things he needed.”

“I feel guilty”

“She wants to die and it’s hard to hear that”

“I can’t leave him”

“If I can’t get her to the Drs, the Dr won’t come to us, so she gets no medical treatment”



What did we find? What did we see? **Continued**

“When she falls we have to call an ambulance every time to help lift her”

“I need a break to get out and be my own person”

“It’s what you’re expected to do at our age”

“Holding down a full-time job and doing all that needs to be done”



Our findings in more detail

Based on what we heard from Carers who were getting no support, we have ranked the feedback in order of mentions.

| Number of Mentions | Theme | The Issues |
|--------------------|--|--|
| 36 | Psychological wellbeing | Stress & emotion (19) Frustration & having patience (12) Feeling trapped (3) Motivation (2) |
| 21 | Managing 'nursing' tasks | "Managing medication, dressing and personal hygiene" |
| 21 | Having time for all the tasks that need to be done | "Feeding him" "Cooking and cleaning - can't keep on top of it all" "There's not enough hours in the day" |
| 11 | Having 'me time' | I need a break to get out and be my own person |
| 9 | Travel | Getting to appointments and getting out of the house |
| 9 | Communication | "I don't know how best to talk to him" |
| 9 | Feeling isolated & lonely | "Be nice to share the load" "No-one cares" |
| 9 | Tiredness | "I am so exhausted all the time" |
| 7 | Knowledge | "Knowing how to cope" "Not knowing what you are entitled to and how to get it" |

feedback continues on next page ►



Our findings in more detail

Continued

| Number of Mentions | Theme | The Issues |
|--------------------|-----------------------------|--|
| 6 | Coping with their behaviour | "He's changed, he's not the person he used to be" |
| 7 | Knowledge | "Knowing how to cope" "Not knowing what you are entitled to and how to get it" |
| 5 | Financial worries | "We have less money now that I can't work" |
| 4 | Medical | "She gets stressed and can't talk to Drs, so I have to be with her all the time" |
| 2 | Independence | "He doesn't want anyone to help him he is very independent" |
| 2 | Trust | "I don't want anyone in my home" |
| 2 | Adaptations | "He needs a stair lift, but I won't let social services go through his bank account" |
| 2 | 'It's just part of life' | "It's what you're expected to do at our age" |
| 1 | Carers | "They don't have long enough, they are always keen to leave, or cancelling at last minute or not turning up" |



What support do people have?

This group of people told us that they were not in touch with Carers organisations.

64% said that they were caring for someone all on their own, with no other support. Other forms of support were mentioned and are set out in ranked order of frequency in the table below.

| Number of Mentions | Theme | What people said |
|--------------------|-----------------------|---|
| 85 | I do it on my own | "I just get on with it" "We've been married 55 years, it's what you expect" "She's my mum so I just do it" "It's our responsibility" |
| 33 | Family | "My other children help look after their brother" |
| 12 | Friends & Neighbours | "After a while your friends don't know what to do and they leave you." |
| 7 | School | "School was excellent but took ages to get him statemented. KCC refused but the school helped us" |
| 3 | Privately Paid Carers | |
| 3 | Carers orgs | "I had an assessment but was told I couldn't get any help. I am desperate." |
| 2 | Day Centres /Respite | |
| 2 | Trust | "I don't want anyone else looking after my child" |



Healthwatch Kent

Healthwatch Kent is the independent voice for local people in Kent.

We gather and represent people's views about any health and social care service in Kent.

Our role is to understand what matters most to people and to use that information to influence providers and commissioners to change the way services are designed and developed.

Our **FREE** Information and Signposting service can help you navigate Kent's complicated health and social care system to ensure you can find and access the services that are available for you. Call us on **0808 801 0102** or email **info@healthwatchkent.co.uk**



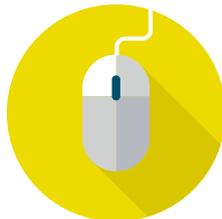
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By Post:

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Healthwatch Kent, Seabrooke House,
Church Rd, Ashford TN23 1RD



Face to Face:

Call 0808 801 01 02 to arrange a visit



By Text: Text us on **07525 861 639**.

By texting 'NEED BSL', Healthwatch's British Sign Language interpreter will make contact and arrange a time to meet face to face.