

TALKING CARE

Stories, advice, ways of
coping and experiences
of the carer's assessment
from carers in Suffolk



David, one of our participating carers

Introduction

Suffolk County Council and Suffolk Artlink worked together with carers in Suffolk to establish how they have found the carer's assessment process and what it is like to be a carer.

This booklet brings together the stories of carers living in Suffolk. Carers have shared their advice, ways of coping and their experiences of the carer's assessment process. Carers have contributed in different ways, some have shared their stories along with their names and photographs, others have just shared their words which are shown in quotation marks throughout the booklet.

We hope this booklet will help to inform you further about the carer's assessment and what the assessment could mean for you.

Who is a carer?

'A carer spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.'

This is the definition given in 'Commissioning for Carers', a resource from the Association of Directors of Adult Social Services.



TALKING
CARE
PROJECT



Suffolk + suffolkartlink
County Council making creative connections

Being a carer

As carers you take on many roles and responsibilities. Each carer's situation is unique, however, many things you feel or experience can be similar.

Our carers have shared their experiences of caring and how this role has affected their lives...



My name is Averil

I have looked after my husband since we got married 41 years ago. My first experience of his depression was just after we got married.

Caring for my husband is making sure he gets up and out of bed, ensuring he keeps himself clean and trying to get him motivated to do things. I have to make sure he has taken his pills and make Doctors' appointments. I try to get him out occasionally.

As a carer you need support, because you can get lost, you need to find yourself and not just be labelled as 'my husband's carer'. Being a carer you don't always have time to stop and think about how you feel, it's all about the other person.

'Occasionally you'll get a hug and a kiss on the head and a "thank you" – those times remind you why you're doing it all.'

'The worst thing about being a carer is the stress and worry that you're not doing it right.'

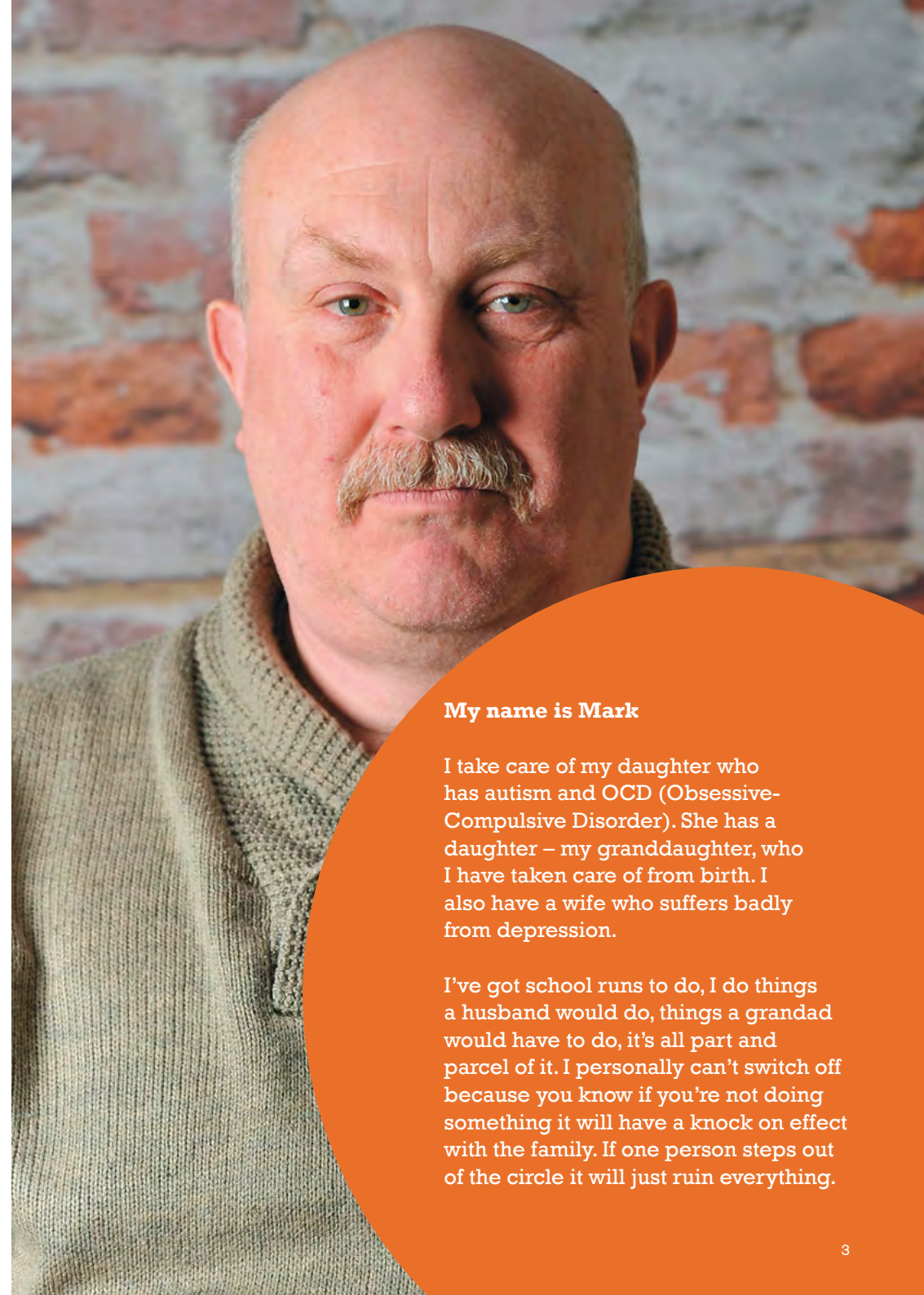
'When the person you care for smiles and says "I love you" it makes it all worth it.'

'I forget to care for me.'

'We married for better for worse; it's not his fault I got the worse.'

'You find your way through because you love them.'

'Caring is hard but when you know you're not alone it becomes more bearable.'



My name is Mark

I take care of my daughter who has autism and OCD (Obsessive-Compulsive Disorder). She has a daughter – my granddaughter, who I have taken care of from birth. I also have a wife who suffers badly from depression.

I've got school runs to do, I do things a husband would do, things a grandad would have to do, it's all part and parcel of it. I personally can't switch off because you know if you're not doing something it will have a knock on effect with the family. If one person steps out of the circle it will just ruin everything.



My name is Pat

I was a carer for my husband for about 15 years. For the last 10 years of his life he had a more unusual form of dementia.

I really didn't become aware of the fact I had acquired the title of carer, until the point I had to seek extra help because I was finding it quite difficult. Each time it was a case of "are you his carer?" and I would say, "no, I'm his wife".

If I had not had all the help and assistance I would not have been able to cope with the things I did, and he probably would have had to go into residential care.

Getting support

As carers it is important that you look after yourself, so you are able to continue caring for your family member, partner or friend, while maintaining your own wellbeing.

Our carers have given their advice for coping and feel strongly that it is important to ask for support if you need it...



My name is Paul

I care for my wife. I have been caring for her for 16 years now, she has dementia and epilepsy.

I didn't know what support was available when I became a carer, it was all new to me, I had never had any involvement in caring at all. I was just struggling on day-to-day, you don't think of yourself as a carer, especially when I was working. I really realised I was a carer when I gave up work and I started looking after her 24/7, that's when it really struck and that was after 7 or 8 years. If I didn't have the support I hate to think where I'd be now.

'When you become a carer it's hard to find the support and information – you have to learn and find out as you go along.'

'It took me a long time to think "I am a carer". People don't always realise they are a carer – it's just an extension of what you do for your loved ones. Then the boundaries blur, when you are washing and toileting, giving personal care, dressing them – this is not the normal role of a family member.'

Advice

Our carers felt they had all learnt important lessons along their journeys. They have shared the advice that they would pass on to other carers...

'Stay positive – you can do this!'



My name is Ann

I have been caring for my dad for quite a long time. I've had him living with me for the last two and a half years.

One of the things I found really challenging was having concerns over my own health. If I did too much, or got too worn out; I would really worry, what if I got sick, what would happen to dad?

It became a sacrifice but also a privilege. To care for a parent like they did for me unconditionally, you just give back and you are glad to do it.

Pat:
Don't feel guilty for asking for help; don't feel that it is your sole responsibility to accept this role that you are in. There is help out there; you have to maybe just seek it out.

'You need to look after and care for yourself too.'

'Listen to others who have been through it and listen to the person you're caring for.'

'Suffolk Family Carers courses were great – the more I know, it helps me cope.'

'We are only human; don't think you have to do it alone.'

Ways of coping

Every carer's role is different but everyone needs some time to themselves and to find ways of coping. Our carers have shared their methods for having a little break and clearing their heads...

'You are looking after someone 24/7, you need a break to go back refreshed.'

'It's important to attend carers groups, a chance to share experiences, learn new coping strategies and off load.'

'Keeping a good sense of humour.'

'Going shopping and getting a cup of coffee – it's time away for me.'

'Moments of sanity – knitting, cooking, listening to birds, word searches.'

'I go to a carers group while my wife is in day care. It's important to talk and support each other.'

'Reading a book is my respite – it helps me escape for a little while.'

A carer's needs

'We all need to feel valued.'

'Care – if you don't look after the carer it will all break down.'

'Information, support, space and time for themselves.'

'Someone to listen to them.'

'Easy access to a support network.'

'To hold on to their own identity.'

'To keep their sense of humour.'

'The company of others.'

Our carers feel there are certain things that are important to maintain in order to keep balance in your life...

'Understanding from family and friends.'

Carer's assessment

Carers have shared their experiences of the carer's assessment process and also how the assessment has been able to help them...

'It was nice to talk about "you" for a change!'

Mark:

When I had a carer's assessment I had two very lovely ladies who visited the house. We talked about what my role is, what I did, how I care for my daughter, what I've been through every day. It was all documented in a way that was comfortable because they could identify what I was actually going through. Once I had done my assessment and my daughter had done hers, we all sat down and had a cup of tea.

You've just got to be honest with the assessor, don't hide anything, tell them exactly what it's like and what you have to do, they want to know how they can help you and you need to tell them what your needs are.

'The assessment outcome is strictly for you – to help you in some way or to give you a break.'

'I was able to pay for gym membership with the direct payment I was offered.'



'Having this time for me allows me to continue caring and looking after myself.'

'The carer's assessment helped so we can afford a holiday together: we got a direct payment which helped to pay for my holiday in Lincolnshire. We can totally relax there; I go fishing while my wife relaxes in the caravan where she is safe'

'The assessment was quite simple and straight forward. Caring can be very stressful, any short break is very welcome and needed.'

Paul:

For me, the carer's assessment gave me respite and allowed me to look after myself: I could go to Slimming World and guitar lessons.

It is of paramount importance you get a carer's assessment and, if you can, join some groups for carers because you get lots of information. If you get a carer's assessment and it's a bit daunting, get an advocate in, a friend or family member, or someone from an organisation to support you.

Carer's assessment (continued)

'It was a nice process – we sat and had a cup of tea, it was like your aunt coming to visit.'

'The carer's assessment was a completely positive experience; the person I talked to was kind and compassionate. It was nice just to talk to someone like that about caring.'

'Very helpful, my assessment felt like a therapy session. It was lovely to talk to someone who knew what I am feeling all the time. It resulted in help with caring for dad. I felt more hopeful after this call.'

'I found the assessment a very pleasant experience. I was put at ease and felt I could say how I was finding caring for my mum, good or bad. I would recommend any carer to use this service as it is an entitlement for you as a carer.'

Ann:

When I had the assessment done I was near to breaking point. I had been non-stop looking after dad for over a year.

When they came to do the assessment she really understood the range of load that there is, the physical, the emotional, the practical and social – these different loads are on you as a carer.

'I got 2 hours a week to help me with my husband.'

How do I get a carer's assessment?

Who can have a carer's assessment?

Anyone who cares (unpaid) can ask for a carer's assessment from the council where the person you care for lives. You can request a carer's assessment, whether the person you care for has an assessment or not. A joint assessment for you and the person you care for is also possible.

Does the person I care for have to live in Suffolk?

If the person you care for lives in Suffolk, then you can contact Suffolk County Council for a carer's assessment. If they live in another county, a carer's assessment would usually be completed by that county and you should contact that council first.

How do I request a carer's assessment?

If the person you care for lives in Suffolk, please contact Customer First:

By telephone
0808 800 4005

By email
customer.first@suffolk.gcsx.gov.uk

Via our website

www.suffolk.gov.uk/adult-social-care-and-health/care-and-support-for-you-and-others/what-is-a-carer/

What should I do if I don't hear anything after I have requested a carer's assessment?

If time passes and you are not advised on when your carer's assessment will be completed, then please contact Customer First who can help.

How and when will my carer's assessment take place?

You should be able to request your carer's assessment at a place and time that is convenient for you. It may be that another local organisation will complete your carer's assessment with your agreement, this will be arranged through your local council.

Preparing for your carer's assessment

Consider your caring role and how it impacts your wellbeing or prevents you from staying healthy, taking part in hobbies, personal goals, working, education, meeting with friends and family, relationships, time for yourself, your choices including continuing your caring role and housing. Have you planned for emergencies?

Advocacy

If you require an advocate for your carer's assessment you can discuss this with your local council too.

After your carer's assessment

Your local council will advise you if you are eligible for support following your carer's assessment and if so, work with you to complete a support plan.

It may be that the best way to support you in your caring role is by supporting either you, the person you care for or both. This may also include relevant information and advice, equipment or a personal budget.



Your local council may or may not charge you for services provided to you as a carer and will inform you of this. Only the person receiving the services can be charged, so a service provided to the person you care for may be chargeable to them, not to you. This will be decided following a financial assessment.

Above: Patricia, one of our participating carers

Poems about caring

These poems are inspired by caring. Written by carers and family members, including a specially commissioned poem by Poet Dean Parkin. The accompanying artwork was created by the carers who shared their experiences as part of the project.

Because I Care

I remember the things I wanted to be
And now I know it's not only me
I won't be playing sport or winning a cup
I will probably be doing the washing up

My wife won't get better there is no cure
And how bad she may get, we are not sure
But we will keep going and try to have fun
As this could have happened to anyone

I don't pack up at the end of the day
And go to the office to pick up my pay
It does not matter if tomorrow is sun or rain
As when I get up I will do it all again

Friends around me don't know what I do
The hours in the day seem so few
I can sit and cry and say it's not fair
The reason I do it is because I care

David Feek
Carer



A Carer

To be able to care for a loved one when they seem
unaware you are there
Takes a very special person with courage and
patience to spare
But when you are praised or commended you look
rather embarrassed and shy
'I am really only a carer' and I have never
questioned 'why'

Dealing with problems and heartaches with fear
gripping you day after day
And then your loved one smiles at you in that old
familiar way
It's enough to keep you going and when people ask
'how do you cope'
'I am really only a carer' my job is to never lose hope

Then just when you think you cannot go on, you're
exhausted and too tired to see
You read in your loved ones eyes the words 'I'm afraid
do please help me'
So when you are asked what your job is I beg of you
take it from me
What you do for your loved one so willingly is Care
with a capital 'C'

Geraldine
Sister of a carer

Piece of Cake

Because it feels like no-one cares for the carer
because it's not a job that you apply for
because it's 24/7
because it could get you time and help
because 'carer' is too short a word for what you do
because you don't know where to turn
because any of the above applies to you
because you've had more than you can take.

First things first – cup of tea, piece of cake.

A carer's assessment is what you need.
It may sound scary, something you dread
like a date with a dentist or coffee
with an Auntie you hate (and the house
is such a mess) but it's only a chat
not a test, a chance to talk to a person
who will listen, can understand, someone
with the best recommendations to make.

Put the kettle on – cup of tea, piece of cake.

It could be a bath lift installed
or visits from a specialist nurse
or have you tried these or maybe those?
Or money to get help with the cooking
and cleaning or time for yourself
(they can see how you're feeling) and day care
an afternoon out or a holiday getaway
because without doubt, you deserve this break.

Let's drink to that – cup of tea, piece of cake.

Dean Parkin
Poet

*Inspired by the words and comments contributed by
carers through the Talking Care workshops and postcards.*



This is a Suffolk County Council project in partnership with Suffolk Artlink. Suffolk Artlink worked with three groups of family carers around Suffolk, working with artists Dean Parkin, Sara Harrington and James Fletcher to creatively facilitate carers sharing their stories.