

# CareLine

*The FREE magazine for unpaid carers in East Sussex*



**In this issue:**

- Caring behind closed doors
- Hastings Direct supporting staff who care
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- Reflections on caring during Coronavirus
- Let's talk about incontinence



A Network Partner of  
**CARERS  
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## Caring behind closed doors: six months on

Carers UK have released their 'Caring Behind Closed Doors: six months on' report which looks at the ongoing impact of the COVID-19 pandemic on unpaid carers, and is based on the experiences of over 5,900 current and former carers.



[carersuk.org](http://carersuk.org)

## Caring behind closed doors: six months on

The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers

October 2020



The COVID-19 pandemic has had a devastating effect on the lives of carers and those they are caring for. The research found that throughout Coronavirus, most carers have had to provide more care than they would usually do. It has left many exhausted and close to burning out and they urgently need more support to help them through winter.

A majority are providing extraordinary hours of care for loved ones with increasing needs during the crisis, often without the usual help from family and friends, and with limited or no support from local services.

As a result, many people providing care have been left exhausted, socially isolated and close to burnout. Adding to these considerable pressures, carers have also experienced a negative financial impact and seen their health and wellbeing decline.

Carers UK are asking for your help in telling the government that they must take more action to support carers. They are asking carers to help raise awareness of the challenges that they are currently facing. Please write to your local MP to share your own personal experience of caring during the pandemic with them. Further information about the campaign and read the full report at: [www.carersuk.org](http://www.carersuk.org).

There are an estimated additional 34,000 carers in East Sussex because of the pandemic.

**If you need support, guidance or to connect, please do get in touch.**

**4 in 5 unpaid carers (81%)** are currently providing more care than before lockdown.

**More than three quarters (78%)** of carers reported that the needs of the person they care for have increased recently.

**Most carers (64%)** have not been able to take any breaks at all in the last six months.

**More than half (58%) of carers** have seen their physical health impacted by caring through the pandemic, while 64% said their mental health has worsened.

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# Welcome to this edition of **CareLine**

Welcome to CareLine. If you look after a friend or relative who couldn't manage without your support, this magazine is for you.

So here we are, at the close of 2020 – and what a year it has been. As I write there is much debate in the media about the impact of coronavirus on day to day life, the economy and Christmas. For so many unpaid carers, the impact has been much greater, as is so clearly illustrated in the new Carers UK research featured on page 2.



Jennifer Twist

Carers have not only lived through the pandemic in 2020, but have done so with the added responsibility and concern for the care of some of our most vulnerable, and with less support with that care. For far too many of our community it has been a year of loss, of worry, of stress and of loneliness.

The support that you have provided to those you care for through the year has been phenomenal. Remembering these achievements reminds us that the events of this year also inspired great solidarity, peer support, and kindness. We were very moved in the summer by the experiences of caring during the pandemic shared by local carers for BBC South East, and more recently by local retired teacher, Paul Harvey, who's composition skills inspired the BBC Philharmonic Orchestra (read more on page 4).

If ever there is a year when carers need a break, it is 2020, so please do get in touch if this is proving a challenge for you - we are here to help. Whatever it looks like this year, I wish you and yours a peaceful Christmas and I hope that you can take some time for yourself to recharge your batteries.

Season's greetings,

**Jennifer Twist, Chief Executive**

## Former teacher with dementia creates and performs music

A piece of music composed by a former music teacher and concert pianist who has dementia has been orchestrated and recorded by the BBC Philharmonic Orchestra and released as a single. Called 'Four Notes', the composition topped the download music charts.

Paul Harvey, who is 80 years old and lives in East Sussex, improvised the piece after being given just four musical notes to play by his son, Nick Harvey, who lives in Crowborough.

Nick recorded his father improvising and playing a two-minute piece from the four random notes and posted the video on social media with the words;



"Dad's ability to improvise and compose beautiful melodies on the fly has always amazed me. Tonight, I gave him four random notes as a starting point. Although his dementia is getting worse, moments like this bring him back to me."

Paul's party trick was to request four random notes from people and compose a tune using the notes. His moving music and playing shows how, despite his condition, his music ability still survives dementia and memory loss.

The video clip went viral and has since received millions of views. The piece was played on BBC Radio 4's Broadcasting House programme to mark Alzheimer's Day on 21st September 2020. Despite being diagnosed with dementia last year, Paul has continued to play and create new pieces from memory.

In a video message posted by Nick, Paul said: "I'm filled with awe that so many people like my music, and the wonderful orchestra and the wonderful arrangement, which I think is lovely. I'm filled with wonder that that's my tune and it's lovely."

The proceeds of the single will be split between the Alzheimer's Society and Music for Dementia.

Find out more about Music for Dementia and download their musical guide developed for people living with dementia and their carers.

[www.musicfordementia.org.uk](http://www.musicfordementia.org.uk)

# Hastings Direct's new initiative to support staff who are carers

**Hastings Direct, the general insurance provider based in Bexhill-on-Sea, East Sussex, is rolling out their carer-friendly initiatives to help colleagues who are unpaid carers looking after someone.**

Hastings Direct has partnered with Care for the Carers and Employers for Carers to support members of their team who are juggling caring for a family member or friend with their job. As a Carer Friendly organisation they will provide training, information, support and assistance for both carers and their managers.

The company has recently introduced a newly trained Carer Ambassador Team to support their colleagues who have caring responsibilities. The team is the first point of contact for carer staff at Hastings Direct who can discuss caring situations, share information that can help carers, such as leave entitlement and flexible working, as well as signpost staff to Care for the Carers.

Suzanne Skilton, Customer Relations Digital Co-ordinator and Carer Ambassador at Hastings Direct, is a carer for her elderly parents with her brother. Caring has been a gradual process, with Suzanne and her brother taking on more as their parents' needs have increased.

Suzanne says; "I think it started last year when Mum was diagnosed with cancer. This meant Dad became her carer but with his spells in hospital, things began to get worse. Eventually it became apparent that Mum needed full time care and she is now in a care home. Dad has care workers visiting him every day as he wants to keep some independence."

"My brother and I feel we were thrown into the world of doctors, hospitals, occupational therapists, physiotherapists, care workers, social workers, and it can feel like you have been on the phone all day just sorting out one problem. Working more from home this year, along with flexible working, has definitely helped."

Suzanne goes on to say; "As a carer for my elderly parents, I really value the support Hastings Direct has put in place by partnering with Care for Carers and Employers for Carers. As a member of our Inclusion Council and a Carer Ambassador, I feel very proud to be part of a company that recognises the responsibilities carers need to balance outside of work, while still fulfilling their role in the workplace. It's great to know carers are supported and have information available to them."



Suzanne Skilton, Carer Ambassador

Richard Phillips from Hastings Direct's Inclusion Council says; "Supporting all our colleagues is at the heart of what we do at Hastings Direct. It is a privilege to be able to offer some help to those with caring responsibilities, who work incredibly hard and often need extra support for the extraordinary work they do both inside and outside of the workplace."

Jennifer Twist, CEO, Care for the Carers, says; "We are delighted that Hastings Direct is taking this important step in recognising their employees who are also caring, and proud to be working with them to make East Sussex carer friendly."

**Five million people in the UK are juggling caring responsibilities with work - one in seven of the workforce. The significant demands of caring mean that 600 people give up work every day to care for an older or disabled relative. Please get in touch if you need support.**

# Get together with other carers

**Joining a carers group offers carers the opportunity to meet up and get together with other carers.**

Groups offer a relaxed and friendly space to chat, unwind and share experiences with other people in a similar situation, in a supportive environment. Peer support can be valuable as there is an understanding and empathy amongst other carers, for instance if you have to leave unexpectedly to deal with something or want to talk about how you feel without being judged. Talking and sharing with other carers can help you and other carers to cope with the stresses and challenges of caring and can offer a regular respite and a date in the diary to look forward to.

Care for the Carers and our partners run and facilitate a range of groups for carers.

***"I don't know what we would have done without Care for the Carers. We meet up a lot, have good chats and a good laugh, chat about our problems, help one another, phone if anything is needed."***

There are groups available for specific needs or interests, including an evening group for working carers, 'Making Memories' Dementia Groups and a monthly Mental Health carers' group for carers of people with mental health issues. We run groups that provide information and advice from experienced carer support workers, and guest speakers on topics that are of interest and helpful to carers.

Our Young Adult Carers (YACs) group offers opportunities for carers to relax, socialise and access support. Currently all of our groups are taking place online or by phone.



Alzheimer's Society offers a Carer Information and Support Programme (CrISP) providing support and carers the opportunity to share experiences in a confidential and friendly environment with others in a similar situation.

Amaze provides information, advice and support for 0-25 year olds with special educational needs and disabilities (SEND) and their parent carers in Brighton & Hove and Sussex.

DISC Dementia Support is a service supporting carers who look after someone with dementia. They are providing weekly, online support groups and information sessions on topics relevant to carers.

## Further information

Get in touch to find out about our carers groups available. Groups are currently taking place online or by phone. Call 01323 738390, email [info@cftc.org.uk](mailto:info@cftc.org.uk). Visit [www.cftc.org.uk/carers-groups](http://www.cftc.org.uk/carers-groups)

**Alzheimer's Society:** 01273 726266 or visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**Amaze:** 01273 772289 or visit [www.amazesussex.org.uk](http://www.amazesussex.org.uk)

**DISC Dementia Support:** Louise 07591 251005, Emma 07591 250988, email [admin@discdementiasupport.org](mailto:admin@discdementiasupport.org)

# Events for carers

## Journaling for wellbeing

Care for the Carers will be running a journaling workshop in February 2021. Journaling is a way to write down thoughts and feelings about what is happening in your life. Journaling can be a stress management and self-exploration tool and help physically, mentally and emotionally. At a time when the days tend to blend into each other, journaling can help to separate one day from the next. It can clear out anxious and negative thoughts, focus our minds and help us to write about positive thoughts, hopes and dreams. For further information about the workshop, contact Hannah, call 01323 738390 or email [info@cftc.org.uk](mailto:info@cftc.org.uk).

## Cooking and recipes

With wintry months ahead, we asked our team to share their favourite delicious recipes that can be made at home and enjoyed. Our Carer Support Worker, Rachel, shared this recipe for an indulgent Kosher chocolate cake that is perfect for Christmas and New Year!

### **Yummy gluten-free Kosher chocolate cake**

#### **Ingredients**

- 340 grammes dark chocolate (finely chopped)
- 114 grammes unsalted butter
- 6 large eggs
- 151 grammes granulated sugar
- 1 teaspoon vanilla extract
- 1/4 teaspoon salt

#### **Method**

- Preheat the oven to 325°F.
- Grease a 9-inch spring form baking pan.
- Gently melt chocolate and butter together in a basin over hot water (bain-marie).
- Place the eggs, sugar, vanilla extract and salt in a large bowl. Beat with a mixer on high speed until the mixture is pale and light and nearly doubled in volume (approx. 3-4 minutes).
- Pour and gently fold the egg mixture into the melted chocolate.
- Pour the mixture into the spring form baking pan.
- Bake the cake in the middle of the oven until it is set.
- Check to see that the cake is done by inserting a cocktail stick in the centre and checking it is clean when removed.
- Allow to cool at room temperature for 10 minutes.
- Run a knife around the edge, carefully tip out and enjoy!



**We will be running cooking classes for carers in 2021. In the meantime, if you have any recipes to share, including traditional, family and cultural recipes, please email them to [hannaht@cftc.org.uk](mailto:hannaht@cftc.org.uk) and we will share for other carers to enjoy.**

# Carers' poetry

We recently ran a creative writing and reflection course with poet, Evlynn Sharp. Here we share Meena and Helen's reflective poems.

## Exhaustion

Try to say something...anything;  
Trying, but the words won't come.  
When in need...  
Say, say speak...  
But there are no words,  
Nothing to utter;

Clarity comes to a standstill.  
The fog has arrived,  
It clouds my thoughts,  
Eats my words,  
And pours down  
Into every limb.

I stumble with each step,  
Getting slower and slower  
With each movement  
That does not belong to me.  
I have become vacant,  
Disjointed from this body.

It's time, way past time  
To put the break on.  
To rest this old sack...  
As I have used it,  
Abused it,  
And expected it to go on.

One more thing  
This girl must do,  
To check on him...  
Have his needs been met?  
Yes.  
Then forty winks is what's needed.

To straighten out the pegs,  
To clear the fog,  
And sink the head into  
The pillow.  
Deep, deep heaviness...  
Then nothing.

**Written by Meena. Meena lives in Polegate and is a carer for her partner who has Multiple Sclerosis.**

## Butterfly Mind

Because I do not have dementia  
I cannot keep up with the pace of your  
forgetting,  
You leave me standing.

I forget that you haven't remembered,  
And I have to tell you  
Again,  
And again,  
And again,

My words are butterflies  
Which disappear  
Without a trace,  
Swallowtail, Tortoiseshell, Peacock,  
All forgotten  
In a trice,

But that one brown moth,  
From last December,  
Here for a moment,  
You remember,

And I know you're right,  
Because I saw it too,

I wish you could forget  
The brown moth,  
Which I never mention,

But you tell me about it  
Again,  
And again,  
And again,

I try to distract you with a glut of  
Red Admirals, Scarlett Emperors, Painted  
Ladies,  
With Beauty, Excitement and Drama,

But your eyes are dull,  
And you only remember  
The brown moth  
From last December.

**Written by Helen. Helen lives in Bexhill and her mother has dementia.**

# Reflections on caring during Coronavirus

**Ben is a carer who has looked after his wife for 17 years. Here Ben reflects on and writes about how the pandemic has affected his caring role and his wife, and his hopes for the caring community.**

"It's impossible to reflect on 2020 without doing so through the prism of the Coronavirus, doubly so for carers. I suppose it makes sense to think over my normal caring challenges, the new problems that face everyone during the pandemic and the additional caring issues it creates before dwelling on the role Care for the Carers have played.

In normal conditions there are things my wife can do, things she can't, then there are things she can do with help or support. This last is the hardest, because it is key to the delicate balance between caring and supporting as much independence as possible. When you get used to someone being fragile and vulnerable it's easy to smother them and hard not to be afraid that you're not doing enough.

***"Fear of getting it wrong has been pretty intense since March."***

My wife, like many others, was advised to remain indoors for several months, and even now she has been told she should go to only a very limited number of places. The fact that it left me doing all the shopping was fine.

The fact that I was doing so while acutely conscious that I was the only possible source of transmission for a potentially fatal virus to which she was extremely vulnerable made me - makes me - extremely careful around others. It's also an interesting challenge to try caring for someone you are not supposed to go within six feet of, as that was one of the strictures of shielding during the height of the crisis. Keeping two metres away from the person you share a small one bed with is hard enough without having to manage their medication and respond to their constant pain.

I think my mental health has suffered more than anything over the last six months and I also think that is where I've benefited most from Care for the Carers.

They have connected me with short term counselling on several occasions and while this is not ongoing, it has in various ways equipped me with the tools to manage better during this time than I might otherwise have done.

As well as this obvious help there have been other things - giving me the outlet on occasions such as this to share my experiences and even the simple fact that whenever I turn up at Care for the Carers HQ I am greeted with recognition and an offer of tea. Sometimes it's good just to feel noticed.

If I had a single hope for the wider carer community it would be that they are both enabled and encouraged to engage more with their mental health. Mental health provision is too limited as it is but I wonder how many people are missing out because they don't see the need or the value. In fact you and everyone around you will benefit if you look after your mind, you will be a better carer, if nothing else. Please seek whatever support you can get whenever you are offered the opportunity."



Ben with pets Apolo and Ivy

***Ben Moore lives in Eastbourne. He cares for his wife, Raven. When Ben is not caring, working or looking after their pets, Apolo, Ivy and Ollie, he enjoys writing and audio books.***

# Let's talk about incontinence

**Healthwatch East Sussex held an online focus group with East Sussex carers to explore carers' views and experiences of continence challenges.**

## Carers on Continence – what are the issues?

Getting support with managing incontinence was a key struggle identified in the focus group. Some carers shared that they hadn't been aware of how to get help. Others had found services hard to access and called for health professionals to communicate more clearly with patients about continence promotion. Another common problem is the expense of incontinence pads, extra bedding and furniture protection, as well as additional cost and work doing laundry. Other practical issues arise when out and about, with non-disabled public toilets having inadequate disposal facilities, and disabled public toilets not actually being accessible.

For some carers, managing incontinence was taking its toll on their emotional, mental and physical wellbeing, given the additional physical work, laundry and housework such as cleaning and changing bed linen. They also shared that the pandemic had caused longer waiting times and delays in accessing continence management services.



## How to get support

It is important to speak to your GP about continence problems, as there may be an underlying cause which could be treatable. GPs will not necessarily know that their patients have incontinence, nor understand the impact on you as a carer, so it is important to raise and discuss the subject with your GP and start the conversation.

## Community Bladder and Bowel Advisory Service

If continence problems persist, you can access the East Sussex Community Bladder and Bowel Advisory Service for a continence assessment.

Patients and carers can self-refer to the Bladder and Bowel Service (contact details on page 11), however some people report quicker access by asking their GP who may refer directly to a District Nurse if the patient is unable to leave the house.

Where continence management issues are a risk or threat to a caring situation, Adult Social Care can make an urgent referral to the Bladder and Bowel Advisory Service.

The Bladder and Bowel Advisory Service can prescribe a limited number of incontinence pads per week or month. However, they do not offer a choice of different incontinence items (such as pull-up pants) and do not offer mattress, sofa or chair protectors as part of the service, so carers may need to buy additional items.

## Concessions and grants

Small grants may be available to help towards the cost of purchasing bed and furniture protection, extra bedding or a washing machine. Contact Care for the Carers for more information. Concessions on water bills might also be available to offset the high water usage resulting from additional laundry and bathing. Speak to your water company to discuss options.

# Incontinence help and support

## Want to talk about continence?

You are not alone in dealing with incontinence, it's more common than you think. Don't forget that we are here to support you. We can assist carers to access continence services and information, so please do talk to us if you need help, especially if you are worried that you may need urgent support with continence management. Contact our team by calling 01323 738390 or email [info@cftc.org.uk](mailto:info@cftc.org.uk)

## Further information and support

We've listed organisations' details below that give continence support and information and provide incontinence products.

### **East Sussex community Bladder and Bowel Advisory Service:**

[www.esht.nhs.uk/service/continence-advisory-service](http://www.esht.nhs.uk/service/continence-advisory-service)

**Telephone: Hastings and Rother area:** 0300 131 4356

**Eastbourne, Hailsham and Seaford area:** 01323 446990

**Southern Water:** [www.southernwater.co.uk/account/help-paying-your-bill](http://www.southernwater.co.uk/account/help-paying-your-bill)

## Other continence information and support

**Bladder & Bowel Community:** [www.bladderandbowel.org](http://www.bladderandbowel.org)

**Bladder & Bowel UK:** [www.bbuk.org.uk](http://www.bbuk.org.uk) and [www.bbuk.org.uk/adults/adults-resources](http://www.bbuk.org.uk/adults/adults-resources)

**Procter Health Care** supplies incontinence pads and equipment. They offer a 10% discount to East Sussex Carers Card holders, with free delivery on orders over £30.

**Visit:** [www.procterhealthcare.co.uk/incontinence](http://www.procterhealthcare.co.uk/incontinence)

**To apply for a Carers Card visit:** [www.cftc.org.uk/get-a-carers-card](http://www.cftc.org.uk/get-a-carers-card)

## Incontinence product suppliers

**Incontinence Choice, incontinence shop:** [www.incontinencechoice.co.uk](http://www.incontinencechoice.co.uk).

Order online or by phone.

**Age UK incontinence shop:** [www.ageukincontinence.co.uk/incontinence-shop.html](http://www.ageukincontinence.co.uk/incontinence-shop.html).  
Order online or by phone.

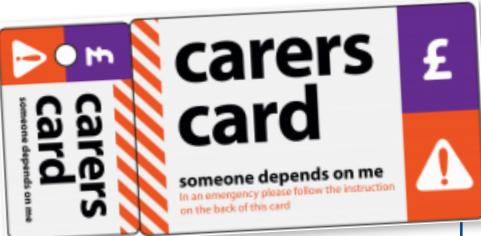
**Boots incontinence shop:** [www.boots.com/health-pharmacy/incontinence](http://www.boots.com/health-pharmacy/incontinence).  
Order online.

Welcome to the latest businesses to sign-up to

# The East Sussex Carers Card

The card has three functions:

- Identifies you as a carer in an emergency
- Emergency respite plan
- A discount card



With an East Sussex Carers Card you can set up a CRESS (Carers Respite Emergency Support Service) plan as part of your carer's assessment. Care for the Carers can help you to set up a CRESS plan if you do not want a carer's assessment.

## Discounts for carers

If you do not wish to put an emergency plan in place but would still like to benefit from discounts for carers, apply for a Carers Card directly from Care for the Carers: Call **01323 738390**, or visit [www.cftc.org.uk/get-a-carers-card](http://www.cftc.org.uk/get-a-carers-card)

This card is also available to parent carers.

Please note that older versions of the emergency alert card are still valid to be used to access Carers Card discounts.

## Please mention the Carers Card when booking.

Don't forget you can get hospital parking for £1.70 at both the Conquest Hospital Hastings and Eastbourne DGH by showing your Carers Card.

To see the full directory of hundreds of services, local businesses, retail and leisure attractions, visit: [cftc.org.uk/get-a-carers-card](http://cftc.org.uk/get-a-carers-card) or call 01323 738390. See the latest offers below, full details online.

Wave Leisure  
East Sussex  
[www.waveleisure.co.uk](http://www.waveleisure.co.uk). Email:  
[memberships@waveleisure.co.uk](mailto:memberships@waveleisure.co.uk)  
Membership offers for carers.

Away Resorts. Tel: 0330 1274747  
[www.awayresorts.co.uk](http://www.awayresorts.co.uk)  
Extra 10% on all breaks for carers.

Town City Cards. East Sussex  
[www.1066local.com/User/MyCards](http://www.1066local.com/User/MyCards)  
Register for a free discount card to use for local discounts and offers.

Procter Health Care Centre  
Eastbourne and Heathfield  
[www.procterhealthcare.co.uk](http://www.procterhealthcare.co.uk)  
Email: [enq@procters.com](mailto:enq@procters.com)  
10% off sales over £10.

Cluttered Minds Ltd. Wellbeing service. Eastbourne and surrounding areas. Tel: 01323 488380  
[www.clutteredminds.co.uk](http://www.clutteredminds.co.uk)  
10% discount off hourly rate.

Procter Health Care Pharmacy  
Polegate and Heathfield  
[www.procterhealthcare.co.uk](http://www.procterhealthcare.co.uk). Email: [enq@procters.com](mailto:enq@procters.com). 10% discount off sales excluding prescriptions.

ejuiceology. the e-liquid specialists  
ejuiceology. Hastings and Rother area  
Tel: 01424 547085  
[www.ejuiceology.com](http://www.ejuiceology.com)  
Free bottle with any purchase of £10 and above.

Are you a business? Sign up to the East Sussex carers card for free.

Offer discounts for carers and get your business promoted.

Contact us

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Please complete. Post to Care for the Carers, **FREEPOST RTAC-GURC-XUJC** Highlight House, 8 St Leonards Road, Eastbourne BN21 3UH

- I am a carer:**
- Please send me future editions of **CareLine** via email instead of post
- Please send me **CareLine** by post
- Please update my address
- Please contact me about the help available
- I would like to be part of the **Carers Voices network**
- I am no longer a carer:**
- Reason \_\_\_\_\_
- Please unsubscribe me from **CareLine**
- Please send me the "**After Caring**" booklet