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My Mental Health  
Carers Group

## Get ready for Carers Week – Making Caring Visible and Valued

Carers Week is taking place on 7th–13th June 2021. The week celebrates and recognises the vital contribution made by the UK's 6.5 million unpaid carers – over 69,000 in East Sussex – and the people who look after a relative, friend or neighbour who couldn't manage without them.

This year's focus is 'Making Caring Visible and Valued', and we're asking carers and the



Willingdon Carers Group

community to come together to highlight and celebrate what you do. Carers and their friends and family, partner organisations and local businesses can all get involved to recognise carers and show support.

Carers are facing many challenges as a result of the pandemic, including taking on more caring responsibilities for their relatives. There are an estimated additional 34,000 carers in East Sussex who are looking after someone because of the pandemic.

More than ever, it's important that we make caring visible and highlight the valuable role that carers carry out every single day in society, sometimes hidden.

Activities during the week and in June include a Walk, Talk and Coffee, online Wellbeing Cruise, Parent Carer wellbeing course, Carers O'Clock Drop-in Day and a cookery session for male carers.

## Free online resources

Teaming up with Carers UK, we are launching free, digital resources on 7th June 2021 to help you with a range of useful carer information in one place. The resources feature e-learning, fact sheets and interactive guides, along with details about our own support for carers. Carer information available includes health and wellbeing information, working and caring guides, e-Learning courses and financial planning resources. There are also resources for young adult carers.

The Jointly app, also available, helps you to share and co-ordinate caring, inviting others to join a 'circle of care' for the person you care for.

We're making Employers for Carers membership available for free to employers with up to 250 staff, to empower employers to support their staff who are also unpaid carers. Membership includes free carer awareness training, networking events and resources to help managers support carers.

Want to get involved and help make caring more visible? Please join our Carers Voices Network to make your voice heard about the big issues that affect you. Members receive regular newsletters and are invited to our Carers Voices Conference in November.

**Get free access to the digital resources by registering on our website at: [www.cftc.org.uk/digital-resources](http://www.cftc.org.uk/digital-resources). More information on Employers for Carers at: [www.cftc.org.uk/employers-and-businesses](http://www.cftc.org.uk/employers-and-businesses). Find out about our Carers Voices Network at: [www.cftc.org.uk/carers-voices-network](http://www.cftc.org.uk/carers-voices-network)**

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## Welcome to this edition of **CareLine**

Welcome to CareLine. I hope that you and yours are keeping well.



Jennifer Twist

It's been an incredibly busy start to the year and we're delighted to soon be launching new services offering more support to local carers.

We are particularly pleased to be developing more specialist support, for example for carers of people with mental health problems. We're also working with Diversity Resource International to reach and empower carers from ethnically diverse communities across East Sussex. Read more on page 9 and watch this space to hear about projects currently in development!

In March, we celebrated young carers and highlighted their achievements, for Young Carers Action Day. This included events for young carers to join, have some fun and meet one another.

As I write, we are preparing for Carers Week – in June we'll be taking part in the national campaign to Make Caring Visible and Valued. We're inviting local carers, partners and the public to join us in celebrating the huge difference that you make to our communities and the people you care for (see page 2).

And I'd like to end with a thank you to all the supporters and funders of Care for the Carers and all carers' services locally. Without you, our work would simply not be possible. I am especially in awe of Barbara Vitler, who will be doing a 10,000 feet skydive to fundraise for carers! You can read all about her endeavour on page 4 – please do join me in supporting Barbara if you can!

Jennifer Twist, Chief Executive



## COVID-19 vaccination rollout in Sussex - information for carers

Carers in Sussex are eligible to receive the COVID-19 vaccination now. If you have not received your vaccine and would like one, register with us and we can help you get your vaccination to help protect you and the person you care for.

- Register with Care for the Carers online at: [www.cftc.org.uk](http://www.cftc.org.uk) or by calling us on: 01323 738390. We will help you access the local vaccination services via your GP-led local vaccination service, or:
- Book online via the national booking service at: [www.nhs.uk/covid-vaccination](http://www.nhs.uk/covid-vaccination), or by calling 119.

You can keep updated with the latest Sussex vaccination information on our website at: [www.cftc.org.uk](http://www.cftc.org.uk).

## A giant leap for carers

Care for the Carers supporter, Barbara Vitler, is skydiving to raise money for our work to help more carers. Barbara will be jumping 10,000 feet with her granddaughter, Hazel, as part of her 16th Birthday celebrations.

Barbara says: "Hazel has wanted to do a skydive since she was 12 and asked me to do one with her. I agreed, never thinking it would actually happen! We have decided to support Care for the Carers because they have helped me as a carer, and they are there for all unpaid carers across East Sussex, supporting over 7,500 carers a year. Seven years ago, I became a full time carer for my parents, and didn't realise the toll it can have on your mental and physical health and how your whole life is put on hold whilst caring. They supported me massively, introducing me to other carers, provided a network of support, and made me realise I was not alone. Care for the Carers is very important to me, and I would love to give back to this amazing charity."



Thank you, Barbara and Hazel, for doing this amazing feat to help carers!

**If you would like to donate, you can donate online at: [www.justgiving.com/fundraising/barbara-vitler](http://www.justgiving.com/fundraising/barbara-vitler) or send a cheque to our office, our address is on the back page.**

# Carers give their feedback

Earlier this year, we asked you to complete our annual survey and share your opinions and experiences about your caring role, how Care for the Carers supports you, and how we can plan our services to support you better.

## What you said

- **96.6%** reported that, overall, you are satisfied with Care for the Carers
- **85.7%** carers said that, at the time of the survey, you continue to feel the negative impacts of the pandemic on your caring role
- **91.2%** say that the information, advice and guidance has helped you to make informed decisions.
- **91.4%** of carers feel that your own health and wellbeing has improved with our support.

**"You do a great job already, keeping us supported and informed. I would say just keep doing what you are doing and thank you."**

The survey reflected and highlighted the challenges that carers are experiencing, with 100% of you saying that you feel stressed, 91.2% feel isolated and 85.7% of carers are feeling the negative impacts of COVID-19.

Not surprisingly, we also found that 59.7% of carers have issues with finances and the ability to work has affected 66% of carers.

## Respite care provision

15% of carers had accessed respite in the last 12 months and 25% had not – but would have liked to. Barriers to accessing respite include respite provision stopping

because of the pandemic and carers not being aware of the respite that is available.

**"Due to Covid, my husband hadn't been to his day centre and I haven't been able to go to have my respite activities."**

## Support needed by carers

Carers said that the support you need the most are emotional support including counselling and non-judgemental listening support, and information, advice and guidance.

## Other feedback

Carers also gave feedback and made suggestions for service developments and communications. Specific feedback about our communications was mainly positive.

**"I am happy with the regular bulletins and the effort to regularly review the services available during the present crisis and to present your work in an easily digestible form."**

## Carers voices

Carers have opportunities to give feedback about services and debate the issues that affect you by joining our Annual Carers Voices Conference, which will be in November this year.

You can also join Carers Voices Focus Groups throughout the year, giving carers the chance to share views and experiences on a range of subjects. Recent focus groups include care homes and the experiences of Sussex carers with health and care during the pandemic.

**Find out more: [www.cftc.org.uk/carers-voices-network](http://www.cftc.org.uk/carers-voices-network) or call us: 01323 738390.**

**We are here for all carers, so if you are experiencing difficulties, need support or would like to connect with other carers, please do get in touch.**

# My mental health carers group

**Anna Newman looks after her husband, Thomas. Here, Anna writes about her caring role and meeting with the Care for the Carers' Mental Health Carers Group.**

"My name is Anna, and I am from Lewes, East Sussex.

I have been a carer for my husband, Thomas, for 10 years. Thomas has Schizoaffective Disorder which is a severe mental illness. He suffers from audio and visual hallucinations, as well as depression and delusions. He also has some physical health issues. Thomas has recently been diagnosed with treatment resistant Schizophrenia, meaning that after trying many medications, nothing has worked.

I help my husband with medication, preparing meals, emotional support and arrange to take him to all medical appointments. I also have to prompt him to remember to do certain things, as when he is partially unwell, he can struggle with his memory or lose track of time.

Before the COVID-19 lockdown, I used to go to the monthly Lewes carers' group; this now takes place online. I also take part in the monthly Mental Health Carers Group which started last year. I find this group particularly helpful as I can relate to the struggles that come with caring for someone that is mentally unwell. It is nice to share stories and stresses with a group of people who completely understand what you are going through.

It is also good to have time set aside for something that benefits my own mental wellbeing and to meet other people in a similar situation.

Even before lockdown, being a mental health carer can be quite isolating at times. People don't always understand

the severity of the illness or why sometimes plans have to be cancelled at the last minute, or the reason a person may behave in a certain way when they are unwell.

We have faced discrimination in the past, and some people are keen to offer unsolicited advice on a subject they know little about. Thomas and I only surround ourselves with friends who love and support us for who we are. We are very open about Thomas's diagnosis; education is key to ending the stigma surrounding mental illness.



Anna

I have previously attended activities arranged by Care for the Carers. It was nice to socialise with other carers and be spoilt. I would recommend joining a carers group as it is a great way to meet new people, share stories, get support and find out about other services you may not be aware of."

Carer Support Worker, Rachel Lawson, who facilitates the group, says: "We provide a safe, confidential space for those caring for someone with significant mental health difficulties to be able to talk openly and honestly about the challenges they face, and to support members to feel less isolated, lonely or judged."

"Sharing experiences and focusing on the incredible skills that carers have is an important part of peer support."

**Get in touch to find out about all of the carers groups available. 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)**

# Events for carers

**With lockdown easing, we are so delighted to be able to gradually reintroduce events and get together, and can't wait to see you soon. We are continuing some online opportunities too, which have proved to be more convenient for some carers.**

## **Carers Week Walk and Talk with Coffee**

Join our accessible, relaxing walk at beautiful Gildredge Park, Eastbourne, on Thursday 10th June at 10:30 am. Take a leisurely stroll with other carers and enjoy the outdoors. Social distancing rules will be observed. Free. To book, contact Hannah, phone: 01323 738390, or email: [info@cftc.org.uk](mailto:info@cftc.org.uk).

## **A week of activities for carers**

During Carers Week, Association of Carers are holding online activities on Zoom. Sessions include chair yoga, coffee and chat, creative writing, craft, knit and natter and an art session. The activities will be fun, friendly and informal. Free. To book, phone: 01424 722309 or email: [jane@associationofcarers.org.uk](mailto:jane@associationofcarers.org.uk). More information: [www.associationofcarers.org.uk](http://www.associationofcarers.org.uk).

## **Take a Carers Wellbeing Cruise**

You're invited aboard a Wellbeing Cruise with Coastal Wellbeing on Wednesday 9th June, 1pm-3pm. Take time for yourself to have fun, meet other carers and explore wellbeing. Free. Contact Molly, phone: 07507 734370, email: [molly@coastalwellbeing.co.uk](mailto:molly@coastalwellbeing.co.uk) or Lucy, phone: 07598 323254, email: [lucy@coastalwellbeing.co.uk](mailto:lucy@coastalwellbeing.co.uk) to book your place and for more information.



## **Cookery course for male carers**

Community Chef, Robin Van Creveld, is holding a hands-on, five-week cookery course for male carers. Learn to prepare delicious, affordable and healthy dishes using everyday ingredients as well as meet other people. The course starts on Tuesday 29th June through to Tuesday 27th July 2021, 11am-2pm. It takes place at the Lewes Community Kitchen which is close to public transport. It costs £5 for the five-week course and all ingredients are included. To book, contact Robin by email: [office@communitychef.org.uk](mailto:office@communitychef.org.uk) or call: 07766 526217.

## **Carers O'Clock Drop-In Day**

To celebrate Carers Week, carers are invited to join a free, drop-in day of creativity, conversation and a delicious lunch on Tuesday 8th June, 10am-6pm. There's activities, a free Carers O'Clock goody pack and you can also find out about services and support available. Enjoy drinks and lunch prepared by a professional chef. For more information and to book a place, email: [info@cultureshift.org.uk](mailto:info@cultureshift.org.uk) or just drop in anytime during the day. This event will take place at Community Wise, Ocklynge Road, Eastbourne BN21 1PY.

**Take a look at all of the events available on our website at: [www.cftc.org.uk/whats-on](http://www.cftc.org.uk/whats-on), or get in touch.**



# Sussex carers share their views on healthcare during the pandemic



As part of The Sussex Carers Partnership (formed of Care for the Carers, The Carers Centre Brighton and Hove and Carers Support West Sussex), we were commissioned by the Sussex NHS Commissioners to conduct a research project and gather the views of carers across Sussex, focused on health and care during the pandemic and the challenges faced when accessing healthcare. Carers across Sussex were given the opportunity to have their say and share their experiences.

Carers took part in our Carers Voices Conference and a survey and were invited to join a series of discussion workshops. In March, the research findings, along with six carer-led recommendations, were presented to carers and key decision makers from the NHS, CCG and local Commissioning Managers for East and West Sussex.

The main conclusions of the research following engagement with carers are:

- Communication between carers and healthcare providers is seen as inconsistent and leads to highly variable outcomes. Already an issue for carers, this has been exacerbated by the pandemic
- The negative impact of caring on mental health (including loneliness and isolation) is one of the single biggest issues expressed by carers

- Identification of carers and recognition of carers' expertise by healthcare services is generally seen as haphazard or poor
- Delayed and cancelled appointments and services because of the pandemic are still a concern.
- Back-up for carers and respite is critical
- Uncertainty about when and how carers will access the COVID-19 vaccine and concerns about the reasoning behind those they care for being vaccinated earlier than carers.
- COVID-19 messaging from NHS and Government is ranked highest in terms of carers' levels of trust, however this is not universal.

## Recommendations

Recommendations from the research conclusions will be considered, and where agreed, actioned by Sussex NHS Commissioners. Recommendations include:

- Incentives to identify carers
- The introduction of mandatory carer awareness for all healthcare staff
- Centralised carer records
- To reduce the negative impact of caring on mental health
- Regular and consistent messaging to carers about the COVID-19 vaccination programme, and continuation of non-COVID-19 services
- To produce a clear road map for services and support and options for carer support.

**With further work to be done by the NHS to determine the feasibility of implementing the recommendations across Sussex, we will inform you of future progress of this project.**



# Supporting ethnically diverse carers

We're excited to work with Diversity Resource International (DRI) focusing on supporting and empowering carers from ethnically diverse communities in East Sussex.

**Ruqia Osman, Race Equality Community Development Worker, DRI, explains more.**

"We're delivering a project that will identify and address the barriers that carers from ethnically diverse communities face. They have the same challenges as all carers, however, they face additional barriers such as cultural and language barriers which can increase the risks of poorer health outcomes, poverty and social exclusion. There are two initiatives involved with this project: a peer support carer group and research focus groups.

## Peer support carer group

Facilitating this group, we'll be working with diverse carers to identify and address the barriers they experience when accessing support and engaging with local services. The group can help to build a middle ground for increasing carers' confidence and trust to access the help they need. The eventual aim is for the support group to be led by carers for carers in diverse communities.

## Focus groups

The focus groups will be held in Rother, Hastings, Eastbourne and Bexhill and will give ethnically diverse carers the opportunity to have their voices heard by sharing their views and experiences of the barriers and struggles they face. Carers can really get involved and be part of the change they would like to see. Recommendations from the groups' feedback will be shared with East Sussex organisations to influence changes to support services.

## Challenges

These initiatives will address the cultural and/or religious challenges that can prevent carers feeling comfortable and

confident to access local services. According to Carers UK research, ethnically diverse carers experience higher rates of poverty. There can be stigma associated with caring for a family member, for instance with mental health issues. Carers can also feel fear or shame, which prevents them from seeking external help - and can be perceived as interference.

## Carer awareness

There is a lack of awareness of what an unpaid carer is, so people don't identify themselves as a carer and therefore won't have the knowledge that support is available.

With local, diverse communities, there are specific and varied needs that can impact accessing culturally appropriate

services. This project will give insight into the individual experiences that carers are having, and their associated different needs and issues.



## Language

Language is a key barrier as information is mostly only in an English format, so there is no access to information that can be easily understood. Similarly, some ethnically diverse carers may not be able to communicate nor inform local services of their needs because it is a struggle to be understood, and therefore be heard."

**If you are a carer from an ethnically diverse community and would like to be involved with the project, or know someone who would be interested, contact Ruqia by phone: 074501 38599 or email: [community@driorg.com](mailto:community@driorg.com).**

# A guide to making a Lasting Power of Attorney

**Making a Lasting Power of Attorney can give peace of mind to you as a carer and the person that you look after. Jessica Shale from Taylor Rose MW solicitors gives a Lasting Power of Attorney guide.**

## What is a Lasting Power of Attorney (LPA)?

The Government's formal definition of a Lasting Power of Attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf.

## Why have an LPA?

An LPA can provide reassurance that if you have an accident or illness and become unable to make your own decisions, those that you trust will be able to take care of your affairs on your behalf.

## What happens if you don't have an LPA?

If you lose mental capacity or become unable to manage your financial and health affairs, without an LPA, you may have no control over who will make decisions for you. Relatives may also have to apply for a Deputyship Order (see page 11). An LPA allows you to appoint people to manage your affairs during your lifetime only.



## What can an LPA cover?

There are two types of LPA available to you. One covers Property and Financial Affairs and the other covers Health and Welfare. Most people decide to have both put in place; however, this is not obligatory and you can choose one or both.

### Property and Financial Affairs

This LPA allows your appointed attorneys to act on your behalf for financial transactions and transactions relating to your property. For example, your attorneys are able to, but not limited to, pay your bills, contact utility companies on your behalf, withdraw money, deal directly with your bank or building society and sell your property.

### Health and Welfare

This LPA allows your appointed attorneys to act on your behalf for specific decisions relating to your health and your welfare. For example, your attorneys are able to, but not limited to, make arrangements and decisions regarding your care, whether permanent residential care, home carers or decisions about life sustaining treatment.

## When can an LPA be used

LPAs have to be registered by The Office of the Public Guardian before they can be used. You are able to choose whether your attorneys are able to act on your behalf for your property and finances either:

1. As soon as the document is registered but with your permission
2. Only if you have lost mental capacity

Most choose the first option as it means that if you are unwell, in hospital, or stuck abroad and still maintain capacity, your attorneys can act on your behalf.

The second option is very much limited to confirmation by a GP that you no longer have capacity to make any decisions regarding your property and financial affairs. Health and Welfare works slightly differently. Your attorneys are able to act on your behalf as and when you are unable to make a decision on a specific aspect of your health, or welfare.

### **How do I know my attorneys will act in my best interests?**

When appointing attorneys, you should always ensure that you name people who you trust to have your best interests at heart. Take time to discuss your intentions with them for the documents and share your thoughts on how you would wish for your affairs to be managed should they need to step in. Any conversations would not be legally binding.

You could also write a letter to your attorneys detailing any wishes you may have; this is only guidance and would not be legally binding.

You can include guidance and restrictions to your attorneys within each type of LPA, should you have particular wishes relating to the way in which they act. Anything in documents must be adhered to in accordance with LPA rules and guidance.

### **How much does it cost?**

The minimum cost to prepare an LPA is a registration fee of £82 per document. So, if you would like both Property and Financial Affairs and Health and Welfare LPAs to be set up, you would pay a fee of £164.

Due to the importance of getting LPAs right and accurate, many choose to instruct solicitors firms to prepare the documents for them and a solicitor will charge their own fees on top of the registration fees.

### **Can I make an LPA for somebody else?**

No, this is not possible. The donor (the person appointing attorneys) must be over 18 and have full mental capacity to be able to make the documents themselves. A Certificate Provider is required to sign the LPA to confirm that the person making them has full capacity and understands what they are signing.

If somebody has lost mental capacity and a carer wishes to apply to manage their finances or health on their behalf, they must apply to the Court for a Deputyship Order.

This works in the same way as an LPA, however, is more lengthy, more expensive, more strict, regulated and comprehensive. I would encourage all who have mental capacity to prepare an LPA to avoid a Deputyship Order having to be sought by a family member later down the line.

**As a supporter of Care for the Carers, Jessica has set up a discount for all Care for the Carers referrals when setting up an LPA. Contact Jessica at Taylor Rose MW solicitors. Call: 01323 405256 or email: [jessica.shale@taylor-rose.co.uk](mailto:jessica.shale@taylor-rose.co.uk).**

**With thanks to Jessica for supporting carers and writing this guide. A full version of this article is available on our website at: [www.cftc.org.uk](http://www.cftc.org.uk).**





# 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)**

**Please show or mention the Carers Card with all offers and discounts.**

This card is also available to parent carers.

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

You can get hospital parking for £1.70 at the Conquest Hospital, Hastings, and Eastbourne District General Hospital by showing your Carers Card.

To see the full directory of hundreds of services, local businesses, retail and leisure attractions, visit:

**[www.cftc.org.uk/get-a-carers-card](http://www.cftc.org.uk/get-a-carers-card)** or call 01323 738390.  
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[hastings.rother@radfieldhomecare.co.uk](mailto:hastings.rother@radfieldhomecare.co.uk)

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**Are you a business?**

Sign up to the East Sussex carers card for free.

Offer discounts for carers and get your business promoted.

Email: [info@cftc.org.uk](mailto:info@cftc.org.uk)



## 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