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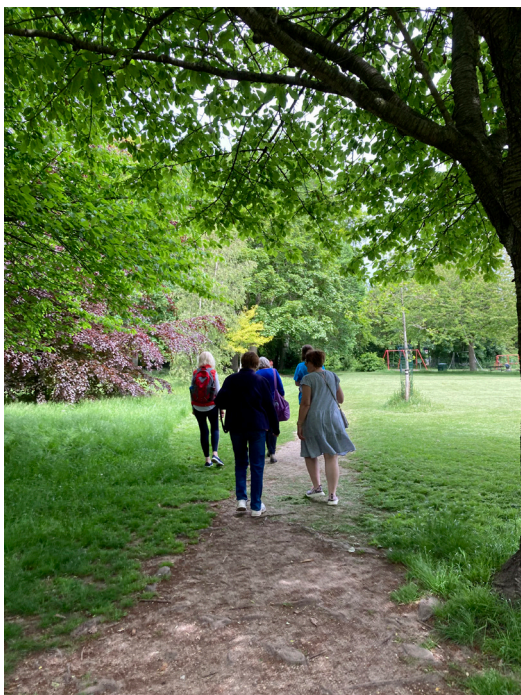


Carers Week 2021

During Carers Week, carers, businesses and partner organisations joined in with the campaign to recognise and highlight carers and the valuable contribution you make to families and communities. A huge thank you to everyone who took part.

Carers Week also saw the launch of the new Carers UK report 'Breaks or Breakdown' which highlighted that many carers are at breaking point. Carers can be on call all the time, not getting a night's sleep and with no time to themselves, or to relax with family and friends. This has been the reality for too many carers, who have had to cope with far less support during the past year than they would previously have received.

After an extraordinarily challenging year providing many more hours of care during the pandemic as well as coping with reduced support from some health and care services, unpaid carers are worried about the support they will have to help them care in the future.



Carers take a walk in the park during Carers Week.

Research released for Carers Week found that carers lost, on average, 25 hours of support a month they previously had from services or family and friends before the pandemic.

72% of carers have not had any breaks from their caring role at all.

Of those who got a break, a third (33%) used the time to complete practical tasks or housework, and a quarter (26%) to attend their own medical appointments.

Three quarters (74%) reported being exhausted because of caring during the pandemic, and more than a third (35%) said they feel unable to manage their unpaid caring role.

Charities are calling on the Government to provide £1.2 billion funding for unpaid carers' breaks, so that those providing upwards of 50 hours of care can take time off for their own health and wellbeing.

Carers were also asked to contact their MP to ask them to show support.

We'll keep you posted on any outcome from this campaign and the report.

You can also share your experience through Carers UK's State of Caring 2021 survey, more details on page 4.

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Do you have a few hours to spare?

We're looking for volunteers to support young carers activities, provide a listening ear to carers over the phone and help us with our social media.

If you are interested, visit our website: www.cftc.org.uk/volunteer-opportunities or get in touch with us.



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Welcome to this edition of

CareLine



Jennifer Twist

Welcome to CareLine, the magazine for everyone who cares for a relative, friend or neighbour in East Sussex who couldn't manage without your help.

If you're new to caring, or maybe aren't keen on the term (let's face it, none of us like being identified by a label), our Carers Rights Day article (page 8) is a good starting point. The term 'carer' may not fully describe the range, complexity and diversity of caring, but as a carer you have a number of rights, set out in law. Understanding your rights, support available and how to access it can be invaluable, so please do take a look.

In June, Carers Week set out to Make Caring Visible and Valued. Thank you to everyone who supported the campaign. It's an important moment in the year for the whole community to recognise the huge role that carers undertake, and pause to understand the reality of caring today. We've heard locally that the challenges of the pandemic were amplified for carers, and this came through loud and clear in Carers UK's "Breaks or Breakdown" report (page 2).

Since Coronavirus measures eased in July, it has been wonderful to begin seeing one another again. There is now a range of opportunities for carers to get together in person, outdoors or in Covid secure environments (see pages 6-7). Understandably many carers need to take things a little slower, so if you're not ready to come along to events yet, rest assured that online and telephone support isn't going anywhere. You can reach Care for the Carers on 01323 738390, or return the Freepost slip on the back page and we'll contact you.

With best wishes,

Jennifer Twist, Chief Executive

Your views on caring

Carers UK have launched the State of Caring 2021 survey. All carers can take the survey which will build a picture of caring over the past year. It is the most comprehensive survey looking into the experiences of carers and highlights caring in 2021, carers' priorities for the future and what support you need to help recover from the pandemic. The evidence from the survey will help Carers UK to campaign for carers to get better support.

The survey will take about 30 minutes to complete, so make a cup of tea, and it closes on 13th September 2021. We will let you know about the research report when it is released later this year.

More information and take the survey:
www.carersuk.org/news-and-campaigns/state-of-caring-survey-2021, or phone Carers UK on 020 7378 4999.

Male carers get cooking!

Male carers joined Community Chef, Robin Van Creveld for a cooking course to learn new culinary skills, make affordable and nutritious dishes and meet other people. The group could also eat what they cooked together and take their meals home.

Bob, (far left), on seeing his cheese scones come out of the oven, said; "I never in a million years thought I could bake something like that. My wife is going to be delighted when I show her what I have made. This has been a huge boost for my confidence. Thank you for an excellent class and a delicious lunch."



Making Wealden dementia friendly

Care for the Carers have signed up to the Wealden Dementia Action Alliance Charter, an initiative working towards making Wealden more dementia friendly and raising awareness about dementia amongst residents and businesses.

Find out more information about Wealden dementia forums, activities and information for carers at: www.wealden.gov.uk.

Adult Social Care - Being Digital

Suzy Dixon is a Project Manager for 'Being Digital', a programme from East Sussex Adult Social Care. Here she writes about how it can help the community.

Whether you embrace gadgets and technology enthusiastically or give it as wide a berth as possible, no one can deny that digital technology is everywhere. For many of us it has become an integral aspect of our daily life.

In Adult Social Care we have embarked on an ambitious programme called Being Digital. It describes our vision for increasing our digital capabilities to help meet the needs of our community and our workforce. Through technology we will



Suzy Dixon

support residents to access the information they need to make choices about their care and support, and to engage with us in a way and at a time that suits them. We want to enable those who can use digital tools to do so, as well as support those who cannot use digital tools but would like to.

Being Digital **is not** about replacing our services with digital only. Instead, we want to make more of our services available digitally. Making services available digitally can bring many benefits, including saving time and effort by making services available at a time most suitable to you.

We don't want to dissuade people from contacting us using traditional methods: we want to offer choice. For some people, digital tools help them make the most of precious free time as well as reduce the cost of travel or remove the restrictions of office opening hours.

One of the digital tools Adult Social Care have adopted is video calling, and we use a product called Microsoft Teams. It allows us to contact carers and clients using our computers and smartphones so that instead of just talking over the telephone, we can also see each other on screen.

You may already have used Zoom, or Facetime, for example, to keep in touch with friends and family, especially during the recent lockdowns.

Although Covid-19 restrictions have eased, Adult Social Care want to continue to offer clients and carers the option of meeting via video call, where appropriate. If you prefer telephone or face-to-face contact, we will respect your choice.

We're interested in hearing what you think and what your experiences have been to date.

We've created a short survey and would appreciate if you are able to take the time to complete it (it should take approximately one minute). It's available at: <https://www.surveymonkey.co.uk/r/HD8QVNQ>

You can also tell Suzy more about your experiences and views of video calling by emailing her at: suzy.dixon@eastsussex.gov.uk.

A paper copy of the survey is available by writing to: Suzy Dixon, Business Development, North A, County Hall, Lewes BN7 1UE.

My dementia carers groups

Ann tells us about her caring role and attending dementia carer groups and activities.

My name is Ann, I am 74 years old, married to Mike for 26 years. I live in Seaford where I have lived for 45 years. I have four children, nine grandchildren and one great grandson.

I am a full-time carer for Mike who has been suffering from Alzheimer's for the past six years and Parkinson's for the last nine months.

What is being a carer like? Well, for me, it is the worst thing that could ever happen to me. Mike can do nothing for himself and cannot communicate which is what I find the hardest thing to deal with, and understands very little; even the simplest of things, like 'stand up' or 'sit down', he just has no understanding of anything. So the life I knew has gone and instead it now revolves around Mike 24/7.

I often spend my days in tears as I just don't know what else to do for him. I cannot afford to send him to a care home as we have very little savings.

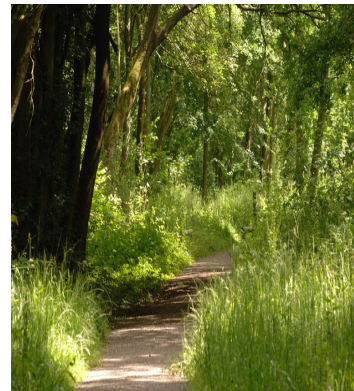
I have found the dementia groups very supportive and are a lifeline for me. I will admit I am not one that easily asks for help and I am very stubborn and will try and do things for myself rather than ask for help.

For the past few years, we have attended the Care for the Carers Dementia Group in Seaford which we have both enjoyed. Mike is not one for crafts as he cannot participate, but it gives him entertainment, especially singing, and he is a different person.

Being with other people in the same position as myself and doing quizzes and other activities helps me. For myself I enjoy the banter and fun that this group brings.

Another group who has done so much for me is Know Dementia. They have literally been my lifeline during the pandemic and have rung every week to check how I am.

We attend a group in the woods at Laughton which for us both has been the most beneficial group that one could ever ask for.



With the group itself, we all got on so well together and I feel as if I have made new friends for life. Some of us would arrive in tears, whether it be the carer or the person with dementia, but by the time we left we would be happy, cheerful, full of life and a completely different person.

At this group the setting in itself was magical with just nature and the bird song to accompany us. We learnt about plant life in what we could eat and how to cook them. We made bird boxes and hedgehog houses which were put up in the woods, we made bracelets out of stinging nettles, and we got so much out of this particular event.

I do feel the groups that are run to help those with dementia are worth their weight in gold. It gives the person with dementia time to enjoy activities that they don't get in their home, and the carer time to themselves to do something they want to do or even just to unwind and relax for a few hours.

Get in touch to find out about all of the carers groups available, or visit www.cftc.org.uk/carers-groups. For more details about Know Dementia, visit: www.knowdementia.co.uk or call 01273 494300.

Upcoming events

There are many free events available for carers across East Sussex. Here's just a few, and check our website and e-newsletter for more activities available, or get in touch.

Get involved for Older People's Day

Older People's Day will be celebrated this year with various events in East Sussex, in person and online, during September and October. Carers can also join local Seniors Forums across East Sussex; it's a great way to stay connected with older people in your local community. Membership is free. Further information and download the events programme brochure at: www.eastsussex.gov.uk/olderpeoplesday. If you would prefer a brochure in an alternative format or language, please call 01273 481565. Paper copies will be available at libraries and other public places. If you cannot find a paper copy, please call Sue Dunkley on: 07783 847944.

Learn to bake tasty goodies

Community Chef, Robin Van Creveld, is holding a five-week baking course for carers. Learn to bake an array of delicious treats, including savoury muffins, stromboli, tarts and pies, cinnamon buns, bagels and much more! Class sizes are small and it's a great way to meet other people. The course starts on Thursday 23rd September through to 21st October 2021, 10.30am-2.30pm, and takes place at the Lewes Community Kitchen which is close to public transport.



The course is free and all ingredients are included. To book, contact Robin by email: office@communitychef.org.uk or call 07766 526217.

Online Wellbeing Cruise

A free, Wellbeing Cruise workshop for carers is available on Wednesday 8th September 2021, 1pm-3pm. Join this wellbeing session to unwind, explore wellbeing and connect with other carers. Online using Zoom.

For more information and to book, contact Molly, 07507 734370, email: molly@coastalwellbeing.co.uk or Lucy, 07598 323254, email: lucy@coastalwellbeing.co.uk.

Caring for your future

Carers are invited to a short, online talk and discussion from Jessica Shale, Associate Solicitor at Taylor Rose MW, on how you can care for the future through Wills and Trusts including information on providing for the person you care for.

It takes place on Carers Rights Day, 25th November 2021 at 11am. The talk is suitable for those who would like to learn more about how they can safely prepare for their future, as well as the futures of those they care for. It is for information only, and there is no obligation to commit to any services spoken about by Jessica. To find out more and book a place, email Amy: amyh@cftc.org.uk, or go to www.cftc.org.uk/whats-on to book online.

All events are on our website at: www.cftc.org.uk/whats-on, or get in touch.

Your rights as a carer



Carers Rights Day takes place on 25th November 2021. Every year, the campaign ensures carers are aware of their rights, raises awareness of carers' needs and lets carers know where to get help and support.

Whether you are a new carer or have been caring for someone for a while, it is important that you understand your rights and can access the support that is available to you as soon as you need it. The Care Act 2014 provides carers with certain rights.

Carer's Assessment

If you are looking after someone who cannot manage without your help, you can approach Adult Social Care and ask for a Carer's Assessment. As a carer you will be entitled to an assessment regardless of the amount or type of care you provide, your financial means or your level of need for support.

The Carer's Assessment is the opportunity for you to define your caring role, talk about the impact it has and look at any changes you wish to make. It will look at the care and support you provide, and how caring affects your life, including your health and wellbeing, any difficulties you have and whether there is anything you would like to change about your caring role.

For example, you may find it difficult to have time for yourself, to relax or to find and keep a job or training.

Following the assessment, the local authority will decide if you are eligible for support.

If the local council decides that you do not have eligible needs, then you must be given a written decision explaining this.

They should also give you advice and information, based on your specific circumstances, about what could be done to prevent or reduce your needs either now or in the future.

Carers who are working

Carers juggling caring with paid work have the right to request flexible working, time off in emergencies and parental leave.

The Employment Rights Act 1996 gives all employees the right to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant. It is at the discretion of the employer whether time off is paid or unpaid.

Flexible working

If you are an employee with 26 weeks' continuous employment at the time you make an application, you have the right to request flexible working. You also have the right not to be discriminated against or dismissed because you have made the request.

Many working carers are juggling caring for someone with family, home and working life. Flexible working can be a way of managing your work-life balance and may help you maintain your work with caring responsibilities.

Flexible working can include:

- working part-time hours
- changing working hours to fit in with care arrangements

Your rights as a carer



- working your usual hours in fewer days
- homeworking for part or all of the time.

Before asking, think about what would work best for you and about the ways it would impact positively on your ability to do your job. If you are unsure of what the proposed working pattern would be like, or your employer is reluctant, you could suggest a trial period to see how it goes.

Your employer does not have to grant your request to flexible working, however they must consider it and give a reason if they refuse it.



Financial entitlements

Find out about the benefits that you and the person you care for are entitled to. It may make a difference to your pension entitlements in the future or bring in extra money to help pay for care. To find out what benefits you may be entitled to, call HARC on 01424 428375 or call Carers UK Adviceline on 0808 808 7777.

Further information and advice

The Care for the Carers team are here to support you with understanding your rights as a carer. We can help you to access the health and social care systems you need.

For a Carer's Assessment, go to: <https://new.eastsussex.gov.uk/social-care/carers> or contact Health and Social Care Connect by phoning 0345 6080191 (calls are charged at your phone company's local rate). Email: hsc@eastsussex.gov.uk, or text 07797 878111.

Keep an eye on our website and social media and in our e-newsletter about Carers Rights Day and how to get involved.

Online resources for carers

Our free, online resources provide a wealth of information for carers, including working and caring guides, your rights at work and seeking support at work.

There are also resources for young adult carers, including information on education and work. Online resources are available at: www.cftc.org.uk/digital-resources.

Employers membership

Support for staff who are carers has a positive influence on carer wellbeing as well as benefits for employers themselves.

For employers, free Employers for Carers membership is available for organisations with up to 250 staff to help carers in the workplace.

Resources include free carer awareness training, line management resources to support carers and networking events. Employers can create a new account at: www.efcdigital.org and use the code: EFC3722.

For useful information about the Care Act and Carers Rights, visit our website at: www.cftc.org.uk. Get in touch with us if you need guidance on your rights.

My kind of world

One carer's journey

Jane writes about her journey as a carer.

My name is Jane and I am a full-time carer, with my husband, to our 24-year-old son who has autism and a learning disability. We also have an older son who lives independently with support. I live with a disability.

Our son has difficulty with planning and organising his daily life and communicating his needs through neurotypical verbal routes so we spend a lot of time doing this for him. Pre-Covid19, involvement - even in his favourite activities - can create huge anxieties. These occasions can lead to a shut down, loud expressive behaviour and difficulties.

During Covid-19, lack of access to these regular activities has also caused huge stress and anxiety with limited understanding of the reasons for all the rules and restrictions.

Despite these anxieties and limitations, we are amazed and proud of all that our sons have achieved.

Covid-19 has amplified all the limitations, as have our son's many experiences of grief through bereavement over the past few years, the most recent being our lovely respite care worker.

There are no specialist services for those with autism/learning disabilities dealing

with this, so we have gathered information to use ourselves but eventually accessed a private counsellor who is very flexible in her communication.

Difficult times, although often extreme and surprising, can and do pass eventually.

Resilience can be hard to maintain through these times, it seems we all have experienced in different ways through the pandemic.

As carers, we do lots of explaining to professionals and voluntary organisations and negotiating his needs. Repeated phone calls, unanswered or inconclusive emails, leaving us feeling misunderstood with no options on the horizon are the name of the game, especially in the post-Covid19 era. Occasionally there is a chink of light and we all whoop with joy.



My tips on coping that may work for you

- **Stay in the moment. Having a rough plan looking ahead is important but flexibility is key.**
- **Happiness often comes from making the small things count. For instance, spending time outdoors in the park, seafront, garden or countryside, having a coffee, reading, speaking to someone close to you.**
- **Have a priority list and be kind to yourself if it doesn't seem to lessen.**
- **Make an emergency plan as it could make all the difference.**
- **In dealing with panic attacks if it all becomes too demanding, focus on senses and identifying five things to focus on.**

Advocating for a family member who has limited communication skills is harder than it appears and outcomes vary considerably. It is often very difficult to pass go and at times can be demoralising and disempowering.

Respite is a big one for carers. The space to be you, whether the time is filled with uninterrupted tasks or rest and relaxation, or catching up with friends.

Speaking between ourselves or making contact with others can be difficult, as our son does not understand the need for discussion, planning activities, tasks and priorities and becomes very anxious loud and repetitive if we talk about things he can't follow. Still, it is important for us so we have to make it happen.

I have joined some online support groups, and while not a particularly tech-savvy person, I am about to launch a new blog website, www.mykindofworld.co.uk, to promote awareness of the bigger picture for those with autism/learning disabilities and parent carers.

I will ask the questions what do good services look like? What makes a difference to your quality of life as a carer? What is your long-term planning for your family members? Are there any local services you would like to see included in a list which may help others?

I would love to hear from other carers, so please do email me with any examples or contributions.

Wishing you all the very best in your own unique journeys maybe we will catch up along the way.

If you would like to contribute to Jane's new website, please email her at: caygilljane21@gmail.com. If you need support, guidance or information, please get in touch with us.

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

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

www.cftc.org.uk/get-a-carers-card or call 01323 738390.

See the latest offers below, full details online.



Brewers Decorators Warehouse East Sussex.
www.brewers.co.uk
Discount on paint in all branches.



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**

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.



1 and 2 beds

A new affordable rental development in Heathfield

Holdenhurst offers enhanced sheltered housing in a thriving, friendly community. It's care enabled, designed for older people who may need extra support to live independently now or in the future.

Open for viewings! Register your interest
Visit www.holdenhurst.org Call 01435 898380



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10% discount on all products in store and for delivery.



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www.eastbourne-leisure.co.uk
01323 738822

10% off casual entry fees for the gym or swimming pool.



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:

- Send me future editions of **CareLine** via email instead of post
- Send me **CareLine** by post
- Update my address
- Contact me about the help available
- I would like to be part of the **Carers Voices network**

I am no longer a carer:

- Reason _____
- Unsubscribe me from **CareLine**
- Send me the **"After Caring"** booklet