



# Caring for carers through the pandemic

Produced by

The Disability Resource Centre

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## **Executive summary**

Carers have been disproportionately affected during the COVID-19 pandemic with increased social isolation, reduced network of support and a lack of wider services and respite. This has negatively impacted the mental and physical wellbeing of carers. Prolonged isolation has significantly impacted carers, compounded by limited access to health and wellbeing services for the carer and cared for person, health services, day activities and some GP services still not fully resumed.

Services have responded to meet these needs including adapted communication and delivery methods, increased communication methods, online activities, and expanded services to respond to the needs of carers.

This report explores the impact of the pandemic on carers and what has been done to respond. The report explores the lessons learned, the successes and challenges and how this can shape services moving forward.

Feedback from carers, identified through local and national sources, and a dedicated carers survey within Luton was completed for this report. Information was also sourced through one-to-one conversations, focus groups, a carers panel and stakeholder engagement.

## The national and local context

The 2015 Carers UK paper estimated the total economic value of the contribution made by carers nationally as £132 billion: an average of £19,336 per carer. This value is estimated to have gone up to £193 billion in November 2020, because of the COVID-19 pandemic. According to the report every day of the COVID-19 pandemic that passes, unpaid carers are saving the UK state £530 million in the care they provide. Previous research undertaken in recent months found that the majority (81%) of carers have been taking on more care since the start of the pandemic and nearly two thirds (63%) are worried about how they will continue to manage.<sup>1</sup>



Luton Council has estimated that around 9% of the population (18,256 people)<sup>2</sup> according to the census in 2011, provide some level of informal care to a relative or a friend. Only a small proportion of unpaid carers are known to health and social care organisations. In March 2021, Luton Council had 1,611 carers known to them on its Adult Social Care system e.g Carers Assessments and Carers Grants. Feedback from surveys of carers indicate several challenges and issues faced by carers.

The impact on carers' can be demonstrated in the summary below taken from the national survey, Facts about Carers 2019:<sup>3</sup>

- Increased financial burden (equipment, heating, laundry and transport) with 39% of carers described their financial situation as 'struggling to make ends meet'
- 43% of carers said their financial circumstances were affecting their health
- 61% of carers said their physical health had worsened because of caring
- 72% said they have experienced mental ill health

- 61% of carers said that they were worried about the impact of caring on their relationships with friends and family
- 81% have felt lonely or socially isolated because of their caring role
- 49% said the difficulty of not being able to get out of the house much has made them feel lonely or socially isolated
- Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours

#### National Adult Carer's Survey <sup>2</sup>

- Quality of life: In Luton, on average, carers report a quality-of-life score of 7.3, slightly lower than the national average of 7.5. There is variation in quality of life between diverse groups within Luton: working age carers report a poorer quality of life (7.1) than carers aged 65 and over (7.7)
- Access to social contact: On average, 31.5% of carers in Luton report having as much social contact as they would like
- Satisfaction with social services: 34% of carers in Luton are satisfied with social services
- Carers included or consulted in discussions about the person they care for: On average, 68% of carers in Luton feel included or consulted in discussions
- Carers' ease of access to information about support: On average, 61% of Luton carers find it easy to access information about support, however this varies by age and gender. Only 57% of 18–64-year-olds find it easy, compared to 66% of 65+year olds, and only 58% of females find it easy compared to 65% of males

## Feedback from carers and stakeholders

Feedback from carers has been sought nationally, locally and through the local carers' service 'Carers Central' and provides a wealth of information on their experiences since March 2020.



### Healthwatch Luton's 'How are you doing' carers survey 2020 – 2021 <sup>6</sup>:

Question: "How are you feeling during the pandemic?"

This question had a varied response. Some people were 'good' or 'well physically' themselves but 'worried for [person cared for].' Many respondents were finding the pandemic difficult and felt they were 'stressed' or 'pretty done right now.'

Words used to describe the feelings of the carers included: '*nervous*', '*frustrated*', '*fed up*', '*stressed*', '*anxious*' and '*isolated*'.

Some carers felt they were 'overall good,' and others were struggling with 'everything being slower than usual'.

Question: 'What is working well with the services you have experienced during the pandemic?'

Hospital consultations and GP telephone calls were noted as being good for some, although it was also mentioned that the follow up from these was 'poor'.

YAWN Life was mentioned as a service working well during the pandemic.

'Not really sure that anything is working well really'.

One person mentioned still being able to access medical appointments during the pandemic for the person they cared for was positive. Having scans has been well navigated for those who have needed them. The Disability Resource Centre was



mentioned for being supportive and this help has been called 'vital' for carers. The Zoom calls with Carers UK were also mentioned.

Question: 'What is not working well?'

There was a wait for over 8 months for mental health assessment for some users and no contact from stroke services, despite a recent stroke.

Communication was an issue for one person, who was unable to find out any information when they needed it or 'even anyone to talk about it'.

Physiotherapy was reported to have not been happening for over a year for one person, which had adversely affected them.

Question: 'How has the pandemic affected the person you care for and has the pandemic affected your caring responsibilities, if at all?'

Some people found it difficult having to amend and change their carers and the number of people coming into the home and other found 'being at home more' had affected them. Further feedback included:

- People 'missing out' on 'vital' activities that support the person they cared for
- Several people mentioned the isolation felt by themselves as carers and the person they care for
- One person mentioned they feel 'trapped together' with their cared for person as they were a clinically extremely vulnerable person who needed to shield and avoid contacts
- Someone noted an increase in anxiety on top of already existing anxiety during lockdown. This exacerbated their contamination OCD and needed to 'accommodate all [their] rules' and being hypervigilant
- Another carer mentioned there being no respite during lockdown. The survey found that less contact with the wider support network (and family and friends) for some carers, with them only leaving home for routines like blood tests

One carer said:

*'I care for my husband who suffers from severe anxiety. Going out now does not give him freedom as he did before the pandemic. He stays indoors and only goes out if he must. I also care for my autistic son who is in a SEN school but due to the rise in cases he cannot go now 'til it is reopened. He does not cope too well without routine and is starting to get more stressed at doing schoolwork. We do take a walk around the block but [this] still does not settle him.'*

## **Carers Central Survey 2022 <sup>7</sup>**

The Disability Resource Centre ran a survey from March to May 2022.

101 respondents completed the online survey. Respondents were mainly carers and family members of cared-for people in Luton and the neighbouring areas.

**98% were affected by isolation (52% badly/very badly)**

**88% affected by poor mental health (45% badly/very)**

**88% affected by lack of access to health services (45% badly/very badly)**

**75% had limited access to respite (44% badly/very badly)**

**88% affected by exhaustion (47% badly/very badly)**

**79% affected lack of access to statutory service (35% badly/very badly)**

*“I finally got carers allowance after 6 months”*

*“I appreciated the phone calls from Sally, very thoughtful”*

*“There was a lot of useful information which I previously wasn't aware of, plus the chance to meet other people in a similar situation who I could talk to”*



## The impact of the pandemic on carers

Feedback from carers has demonstrated the ongoing impact on carers from the challenges over the last two years.

[https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2019.pdf](https://www.carersuk.org/images/Facts_about_Carers_2019.pdf) Feedback from the Carers UK Covid-19 survey of carers, Caring Behind Closed Doors<sup>4</sup> demonstrates the strain on carers through the pandemic with lack of services, effects on health, wellbeing, and finance:

- Over half of unpaid carers (55%) who use day services have reduced or no access because of COVID-19
- Only 13% of carers confident they would get support they need in the next 12 months
- Six in 10 (62%) worried services will be reduced worried about losing access to voluntary sector services because of funding cuts
- One in five unpaid carers who work would reduce working hours or would be at risk of giving up work altogether if they cannot access affordable and accessible care

The Carers UK report the State of Caring 2021<sup>4</sup> also highlighted the following key findings; evidence of the continued impact on carers over the last two years:

- One in five unpaid carers are worried they may not cope financially over the next 12 months
- One in four carers (23%) may not have enough money to cover their monthly expenses
- Carers spend an estimated £1,370 a year on average on services or equipment for the person they care for
- Over half of carers (52%) feel anxious or stressed about their finances

*‘It was very difficult through the pandemic. It was difficult to get support from my GP, Carers Central called me to check I was OK. I knew I could call them if I needed help’*

*“The Disability Resource Centre and Alzheimer’s society provided support and advice”*

The Carers Central team carried out a number of one-to-one and group conversations carers from March 2002 to May 2022. These conversations have uncovered a wealth of information and first-hand experiences of the effect of the pandemic on carers:

- *‘Me and my husband were very isolated during the first lockdown’*
- *‘It was very difficult through the pandemic. It was difficult to get support from my GP’*
- *‘I felt like I have been rather neglected during the pandemic’*
- *‘GPs were not great... there is never any follow-on support or after care to check how you are getting on... years ago a doctor would refer you with a note etc so the person on the other end could get some idea of your issues’*
- *‘I am not listened to as an equal, when supporting the cared-for person at appointments, even more difficult when over the phone’*

The transcript from the carers’ interviews provides examples of how the carers are feeling:

Are you an unpaid carer and how do you feel?

Yes, I am an unpaid carer. I feel that it is not a good situation because as an unpaid carer it’s not costing anybody else anything. I love my family members that I look after, but in some ways if I am unable to work then that puts me in more financial difficulty. If I we are being paid for what I was doing, then at least that means that I would be able to continue quite happily with knowing that I am going to get some money which would cover the times that I have to be unpaid for.

Are you an unpaid carer and how do you feel?

Yes, I am an unpaid carer, I have been for quite a while. The main thing is being tired all the time and feeling like no one notices. So, it would be nice if someone said how are you, every now and again and the isolation. Thank you.

Are you an unpaid carer and how do you feel?

Yes, I am an unpaid carer, I look after both of my parents. My dad has dementia, and my mum is trying to take care of him as well, but she is 78. It is a struggle; they are not entitled to many benefits and trying to even sort out the benefits has been a bit hard and trying to get the help that he needs has been a bit of a struggle as well. They are getting on okay; I do worry about the future somewhat; we are all just trying to do the best we can really in difficult circumstances. As it is my parents, that is what you do, that is your job. So that is what I feel I must do so that is fine. But I would say, the services particularly during lockdown there was not a lot happening. So, there is a stroke association café which was closed so couldn’t attend that and I think it’s the social side of things that have been hard really during lockdown. For him not be able to go out and attend groups, clubs, and things, we are trying the best we can really and just taking it a day at a time.

Are you a carer?

Yes

And how do you feel?

I feel that it is a hard job, but you must do it as your responsibility as a carer.

Are you an unpaid carer?

Yes

How do you feel?

Honest words, yeah very stressed really.

Are you an unpaid carer and how do you feel?

Yes, I am an unpaid carer and I feel that sometimes we are not being listened to by the social worker or the local authority and we must constantly go back to them and explain that we are full time workers in employment and after work we are looking after our family and children, and we need extra help. The local authority is failing to serve their duty it's really stressful, it creates a stressful situation for the family, and I am already going through that.

## **Caring for carers – What we did**

The Disability Resource Centre (DRC) provides 'Carers Central' which is a holistic service for unpaid adult carers in Luton. This service brings a full range of high quality, meaningful services through an end-to-end whole family approach, supporting all types of carers and the cared for person at various stages of their caring 'journey.'

Carers Central meets the needs of a diverse set of carers: adult carers, adult sibling carers, parent carers and carers for those with learning disabilities, autism, dementia, mental ill-health, or addiction. Each can be at various stages of the caring journey including:

- new carer
- carer in crisis
- confident carer
- end of caring journey

Using a three-stage approach, the service supports carers with simple to complex cases.

- Stage 1 – Carers Hub/Contact Centre
- Stage 2 – Case Management
- Stage 3 – Interventions and activities from Carers Central and partner organisations

The service responds to individual needs with a bio/social/psycho approach, supported through a managed journey.

## Case Study

X had their own health-condition, struggling with practical tasks such as supporting their partner while bathing. Their partner had multiple health conditions including dementia, COPD and impact from a stroke. They attended the Equipment Store to purchase a bath lift. A supportive conversation uncovered multiple challenges for the carer and cared for person.

Working with the team we were able to support with the following outcomes:

- funded home assessment with equipment provided including bath lift
- everyday living aids for carer (dining, bathing) and cared for (mobility)
- emergency key cabinet
- carer and cared for able to use accessible fitness sessions
- Carer's Allowance
- PIP for cared-for person
- carers discount card
- carers grant
- access to dementia services
- carer's respite – holiday and residential care facility
- peer support group for carers
- peer support group for carers condition
- training and support sessions
- health and wellbeing information

Stress placed on carers through the pandemic lead to poor mental and physical health compounded by delaying check-ups and treatment, isolation, and economic inactivity. Caring can lead to behavioural change resulting in poor diet, lack of exercise and reduced sleep. The service looked to address underlying causes of stress and poor wellbeing through money management, employment, and equipment services.

Caring responsibilities can change, and carers can be at different stages or can end due to a variety of reasons including health improvement, move to residential care or bereavement and as such their plans are reassessed.

## Effective collaborations

Frontline workers in partner organisations play key roles in helping to identify people as carers, and the specific support they may need. Collaborating with stakeholders in partner organisations the Carers Central service provides signposting information to

the frontline teams. This helps to raise awareness of the Carers Central service, so they can connect carers to Carers Central. Organisations include:

- Council teams
- Blue light services
- Educational establishments
- Bedfordshire hospitals including discharge teams
- Citizens and other advice organisations/networks
- Health services including GP practices
- Jobcentres

Working collaboratively with partners has led to an increased uptake of services. Carers Central has also been promoted through wider organisation such as Citizens Advice, social prescribers, wellbeing services and other charities.

The pandemic saw joint working across local authority boundaries, extending the reach into Central Bedfordshire, Bedford Borough, and Milton Keynes. Organisations such as the local authorities and CCGs (Clinical Commissioning Groups) (Clinical Commissioning Groups) working together in a planned approach for carers across health and social care.

The CCG (Clinical Commissioning Group), VCSE (Voluntary Community and Social Enterprise) and carer support organisations co-produced their strategy with carers through the development of a Carers Panel.

### **Working with the CCG (Clinical Commissioning Group)**

Carers Central has been working with the CCG (Clinical Commissioning Group) to develop an incentivised scheme across GP surgeries in BLMK that will include:

- ✓ Keeping the Carers' Register up to date
- ✓ 95% of carers on the register to be offered annual carers' health checks
- ✓ All carers on the register are offered a flu immunisation in the autumn
- ✓ Practices to provide a report on the number of carers registered at the beginning and at the end of the year
- ✓ Annual report on the numbers of carers having had a health check
- ✓ Manage and keep up to date the carers' notice board and website with carers information (to be checked as part of the practice annual visit)
- ✓ Have a named Carers Champion for the practice
- ✓ The Carers Champion provides an effective link to Carers in Beds/Carers MK/Carers Central – both to bring awareness training and support into the practice and to make referrals to Carers in Beds/Carers MK/Carers Central
- ✓ Providing a seamless referral to carers support services through System One



## **Integrated approach**

Carers Central provided a conduit to connect services and provide holistic support to carers no matter what the point of entry. The 'no wrong door' approach within the model reducing the danger of people falling through the net.

The service is linked to statutory and VCS organisations for inward and outward referral and wider signposting. A managed network with regular two-way communication to keep everyone informed of service offers including network meetings and contributions to newsletters and websites has enabled carers to have access to up-to-date, impartial, and validated information.

The network working with the carers service includes 220 partners such as:

- ✓ Jobcentre Plus
- ✓ Healthwatch
- ✓ Keech Hospice
- ✓ University of Bedfordshire
- ✓ Bedfordshire and Luton Fire and Rescue
- ✓ Bedfordshire Domestic Abuse Network
- ✓ Bedfordshire Emergency Response Team
- ✓ Mutual aid groups
- ✓ Luton and Dunstable University Hospital
- ✓ Age UK Bedfordshire
- ✓ Relate Bedfordshire & Luton
- ✓ Women's Aid
- ✓ Samaritans
- ✓ Cruse Bereavement Care
- ✓ Active Luton
- ✓ Luton Food Bank
- ✓ Bedfordshire and Luton Recovery College
- ✓ CHUMS
- ✓ East London Foundation Trust
- ✓ Afro Caribbean Carers Support Group
- ✓ Ameena Trust
- ✓ Luton Asian Carers Service
- ✓ Pohwer

Carers Central was able to meet carers needs by:

1. Providing a one-stop solution
2. Supporting with multiple issues
3. Providing high quality, rapid and early intervention for carers
4. Close working with wider organisations providing timely and specialist services. This approach provides end-to-end support including seamless pathways in and out of services including support when their caring role ends. This flexible journey supports self-directed support and simple enquiries through to complex case management.

## **Carers Central and Luton Food Bank**

Carers Central worked in partnership with Luton Food Bank to ensure that carers had enough food to feed themselves and the people that they were caring for.

## **Working with NHSEI**

On the 7th of June 2021 Carers Central in partnership with NHSEI invited carers and professionals to get a better understanding of the work and support that has been carried by NHS England and how they can get involved in future developments. Jodie Deards from the Carer and Patient Experience Lead, East of England, NHS England, gave a seminar on the progress made and developments for the future.

The topics included:

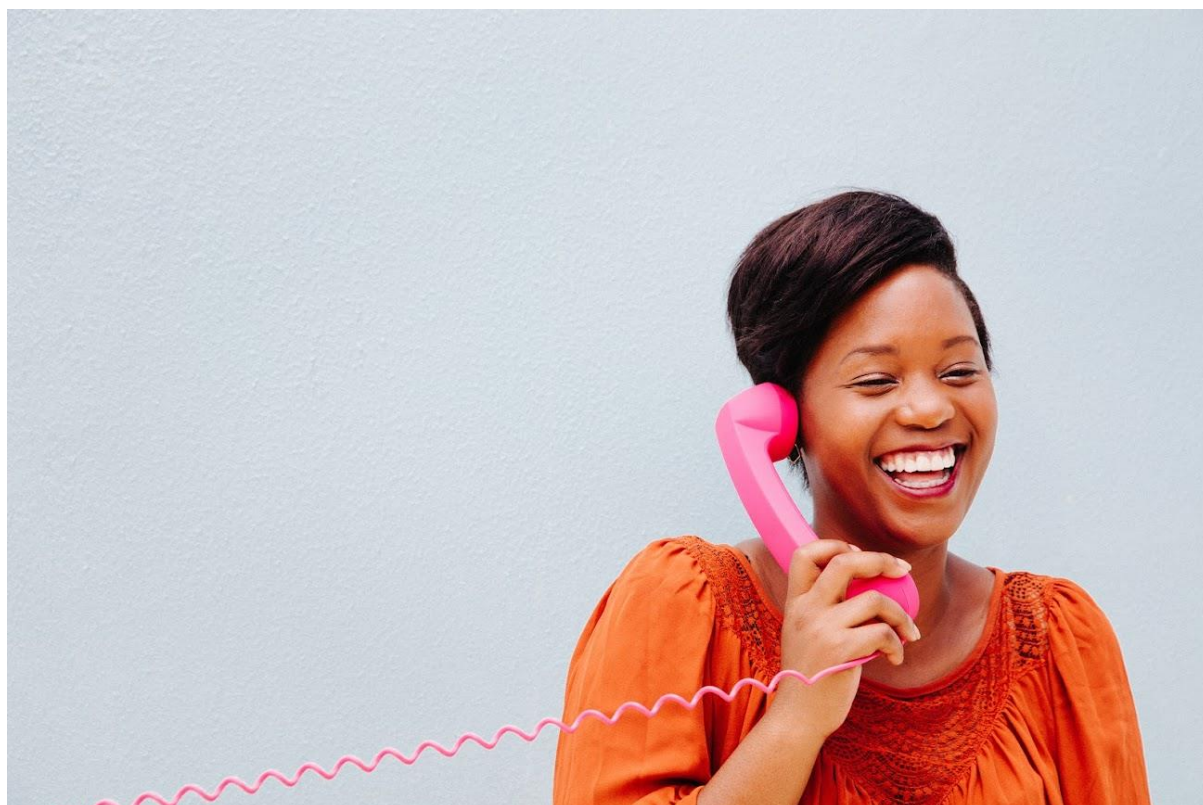
- Code of conduct standard for carers
- Carer contingency planning for emergencies
- COVID-19 vaccine deployment programme for unpaid carers
- How to get involved in future NHS developments

## **GP registration support**

Carers Central worked in partnership with the local Primary Care Network to make carers aware that to get the vaccine you must be registered with your GP. The team supported any carers whose GP would only register those receiving Carers Allowance. They also sent local GP practices information gained from NHS England regarding the best classification for unpaid carers within GP surgeries.

## **Recovery College meetings and Carers Lead Meetings in the pandemic**

Carers Central attended regular meetings with East London Foundation Trust and Carers' organisations to check what support was still out there and get a better understanding of what practical support carers needed within the lockdown.



### **Activities through Covid-19**

Carers Central remained fully operational throughout the crisis. Local information (from partners) was gathered regularly to ensure carers were kept up to date with service information which was frequently changing in line with government guidance. Information was shared through the website, newsletters, and email alerts alongside welfare phone calls to the carers that needed them.

### **COVID 19 training**

Staff with Carers Central undertook COVID related training programmes to support themselves and others to stay safe, and to support carers with their wellbeing particularly with overcoming anxiety during this time.

COVID 19 Psychological First Aid – Supporting frontline workers with issues raised by the current pandemic and how to deliver the best support.

When the centre was getting to reopen the teams were supported in understanding COVID -19 and how to stay safe and work in a COVID secure way.

### **Web content**

Dedicated web content is regularly updated including information on financial support and local services. Information available on the website includes guidance on coronavirus and other essential information such as PPE (Personal Protective Equipment), testing, and government guidance for carers:

<https://carerscentral.org.uk/important-coronavirus-information-for-unpaid-carers/>

Website content continued to be updated with 6,832 web visits over the pandemic and continuing to grow. Google search advertising (through the Google Grant for charities) and social media channels continued to increase traffic to the website. Use of mini stories (case studies) have helped highlight the support carers can receive from the service and the positive impact of accessing support.

Added content included:

Vital information for unpaid carers

<https://carerscentral.org.uk/important-coronavirus-information-for-unpaid-carers/>

<https://carerscentral.org.uk/coronavirus-information-and-links-to-useful-websites-for-carers/>

Wellbeing

<https://carerscentral.org.uk/improving-your-wellbeing-as-a-carer/>

Benefits and Money

<https://carerscentral.org.uk/benefits-for-carers/>

News

<https://carerscentral.org.uk/news-2/>

Events

<https://carerscentral.org.uk/events/>

From April 2020 to March 2021 there were 2,898 visits to the Carers Central website.

From April 2021 to March 2022 there were 3,843 visits to the Carers Central website with an increase of 854 from the year before..

In total there were 6,842 visits to the site for self-help information over the pandemic.

## Face to face services

The survey to service-users <sup>7</sup> indicates that two thirds of respondents prefer to access face to face services at the centre. Once permitted the centre was reopened, following the COVID-19 secure guidelines provided by the government, and is now open to the staff and public on a limited basis. This includes risk assessments,

guidance and safe systems of work, social distancing, traffic management, sanitisation stations and additional cleaning. Once restrictions were lifted a blended approach was adopted.

### **Employment support for carers**

The Disability Resource Centre provides dedicated support for those carers looking for employment. The programmes explore how carers learn, their strengths and how they can develop further. Carers are encouraged to explore their hopes and desired goals, with suggesting ways to reach their desired goals. They can learn how to relax, de-stress and find balance in their life, with a range of wellbeing support, online courses, and workshops. The programme can help with confidence building, exploring ambitions and setting plans to achieve them; all helping to build a positive future.

With these building blocks in place, carers look at suitable opportunities for paid work, developing employability skills and access to further training and support. This can include:

- ✓ Identify transferable skills and strengths
- ✓ Exploring different work options
- ✓ Skills health checks
- ✓ Write a winning CV
- ✓ Excelling in interview
- ✓ Covering letters and emails
- ✓ Making the best job applications
- ✓ Volunteering opportunities
- ✓ Self-employment
- ✓ Support in the workplace
- ✓ Exploring local work opportunities
- ✓ Support to apply for jobs

### **Activity Central fitness and wellbeing**

Carers were provided the opportunity to engage in wellbeing and fitness sessions to help them stay physically active. Sessions were available as live online sessions or pre-recorded videos to watch at a convenient time. Sessions included:

- ✓ Yoga (chair and non-chair based)
- ✓ The Whole-Body Workout
- ✓ Chair based exercises (using the chair, ball and bar as props with the music)
- ✓ Cognitive & memory sessions (memory stories with movement and exercise)
- ✓ Low impact cardio class
- ✓ Boxercise
- ✓ Bands, balls and bars

## Care Academy

The Care Academy offers a range of workshops including all 15 units of the Care Certificate and condition specific training such as dementia, autism and learning disabilities. This accredited learning includes emergency first aid. These can be accessed by carers free of charge and are available through online learning and virtual classrooms.

**Wellbeing Matters** - 'Wellbeing Matters' aims to empower carers to be active, make positive changes and improve their mental and physical wellbeing.

Objectives include:

- ✓ recognising the importance of their complete wellbeing
- ✓ increased awareness of healthy lifestyle choices
- ✓ improved emotional resilience
- ✓ reflecting on the present and planning

**Money Matters** – this programme supports carers to develop their financial management skills, maximise income and empower carers to make positive changes to improve their economic wellbeing. Learners are supported to take control of their financial situation and progress into further learning, employment, and volunteering.

Carers are guided to recognise their current financial situation and to learn skills to manage their money and make positive changes in their behaviours and attitudes to money. Money Matters supports unemployed or economically inactive individuals to improve their financial capability and situation to tackle out of work poverty, alongside enabling them to be more ready to move into employment. Objectives include:

- ✓ Exploring behaviours, habit, values, and attitudes
- ✓ Accessing online tools and information
- ✓ Identifying opportunities to maximise household income
- ✓ Understanding their expenditure and ways to save money
- ✓ Developing employability skills
- ✓ Breaking intergeneration cycles of poverty

## Social and peer support

The main issue for carers has been the isolation and lack of face-to-face support. Support was provided for Carers Central and other services with weekly welfare phone calls.

Carers Central and local providers provided opportunities to meet online. This included peer groups such as CEDA, carers coffee mornings and the Afro Caribbean Group. Online sessions such as Yoga and fitness were held along with one-to-one



meetings with a Carer Support Officer. Wider support including wellbeing webinars from the local CCG and activities through Active Luton were promoted to the carers.

Newsletters also promoted the local opportunities available to carers to connect with others.

### **Practical COVID-19 support**

The carers service (Carers Central) provided a conduit to share key messages with carers through web and social media content, newsletters, and email alerts regarding information on carers for vaccinations, eligibility and registering with the GP as a carer.

Content also including information and links to government guidance and staying safe. This was vital when information was frequently changing.

Carers Central liaised with the local authority regarding the supply of PPE (Personal Protective Equipment) to unpaid carers across Luton when packs of aprons, visors, gloves and masks were provided.

Working with Public Health lateral flow tests were available from The Disability Resource Centre.

### **Carers' Letters**

In response to enquiries from carers, Carers Central helped carers to demonstrate that they are essential workers during the pandemic. Carers Central worked alongside Luton Council to produce a letter for unpaid adult carers in Luton. These are issued by Carers Central. This allowed carers to gain access to support during the pandemic including access to supermarkets and additional support for unpaid carers.

### **Carers wellbeing packs**

Carers Central continue to work in partnership with The Inner Wheel Club of Luton North regarding donations which include toiletries, gift boxes, scents etc. These are used to create further wellbeing packs to provide small presents for unpaid carers within Luton, who are feeling overwhelmed within their caring role.

### **Wellbeing support**

Over the course of the pandemic, Carers Central continued to carry out welfare calls to unpaid carers who may have been in isolation or unable to see their loved one in a care home or hospital due to Covid restrictions. Some carers even cancelled their paid carers and carried out the caring role themselves while in lockdown, to ensure the safety of their loved ones. We have worked with individual unpaid carers to produce a carer's action plan around their wellbeing.

## **Case Study 1**

The carer was suffering from stress and anxiety due to lockdown and her caring role; she looks after her mum in partnership with her dad. The carer saw things that she felt the social worker needed to be aware of, but dad unfortunately did not have the same view and caused a number of disruptions within the home including both of their caring roles. The carer was supported to look at several areas of her life which she felt may be having an impact on her wellbeing, once this was done an action plan was created to keep progress. Support was given on a weekly basis to look at progress being made and any issues that they have had to overcome.

The carer is now in a better place and is now working in partnership with her dad to ensure her mum has the best possible care. The carer has taken time out to go away and take a break without feeling guilty; the carer has also joined a dieting programme and goes for walks on a regular basis.

## **Case Study 2**

Carer has been caring for their 19-year-old son who has mental and physical disability and is bedbound unless supported to get up. They felt like they wanted to take their son and three siblings away for a weekend to help enhance the wellbeing of the whole family as the COVID lockdown has had a big impact on their family.

Support was given to the client to apply for the Family Fund, and an application was filled out in partnership with the family.

The family have been told by Family Fund that they have been successful in their application, but they just need to choose one of the four areas. The family have decided to go for Communication and Days Out. Because their son is unable to speak or communicate when he is hungry, hot, cold or in pain, they feel that a communication device to help support his communication with the family would be good. The family have planned several days out with all siblings to help support their wellbeing.

## **Post caring support**

Many services ceased to support an unpaid carer once their caring role had stopped and left the post carer in isolation to deal with family loss and other financial and medical affairs. Carers Central recognised that post unpaid carers need as much support as people still within the caring role.

## **Case Study 3**

Carer came to the Carers Central with several concerns as a post unpaid carer. Client's mum was the main carer for their dad, who passed away due to Covid19. The carers mother had several medical conditions and safeguarding concerns, it was considered best if the client's mum moved into the client's house with him and his brother. They also felt that they needed support as a family to deal with their loss.

The carer was supported to request a risk assessment for his mum; mum also has mental health issues due to the death of her husband; this also had an impact on the client and his brother. Client was supported to request talking therapies for his mum, brother, and himself. They were supported to obtain a carers assessment to look at his wellbeing needs regarding his caring role.

The carers mother has been assessed and support is in place to help her with everyday needs. The carers mum and brother's wellbeing are being supported regarding their sudden loss. and the carer is addressing his caring needs and wellbeing.

### **Improved awareness of Carers Central**

Promotional resources were updated and distributed electronically and in hard copy across community locations and via key partners, local groups, and health services.

Working with the CCG to improve contact with health care settings included meeting with PCN practice managers, carers planning groups and sharing information via CCG communication channels.

Collateral to increase exposure of the 'Are you are Carer?' messaging, which is seeking to prompt carers to self-identify when caring for a loved one.

Stakeholder engagement included meetings and sharing information with stakeholders and referral agencies such as Mind, Autism Bedfordshire, Alzheimer's Society, Tibbs, and CHUMS.

To support all frontline workers in the local authority and agencies Carers Central produced a leaflet which can be shared with their staff to signpost any carers to Carers Central.

### **Newsletters**

Regular newsletters included information about Carers Central and information from partners. This included important information regarding COVID-19, services available to carers and accessing wider information.

The newsletters have been sent to the distribution list of over 1,700 carers which can also be accessed through the Carers Central website.



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# Luton Carers' Handbook

Practical information for unpaid carers in Luton

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Updated: April 2022 (Edition 2)

Produced by Carers Central which is provided by The Disability Resource Centre

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

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## Carers Handbook

The Luton Carers' Handbook aims to provide carers with more information and resources about their caring role. The handbook is available in sections, as standalone information sheets or as an entire booklet.

Sections include:

- Are you an unpaid carer?
- Carers rights and the Care Act 2014
- Carers Central support
- Carer's Assessments & carers breaks
- Assessment support
- Carers' wellbeing
- Carers' benefits and money
- Employment support

- In work support
- Training
- Volunteering
- Disability equipment
- Equipment and everyday living aids
- End of life care
- Resources on medication, condition, and disability information
- Peer support and local groups
- Additional care needs
- Useful local contacts
- National helplines
- Frequently Asked Questions (FAQs) and answers

It can be accessed via the Carers Central website or be downloaded as an entire booklet. Hard copies can also be requested.

### **IT (Information Technology) support**

Carers Support Officers are at hand to support clients with accessing information online as more services and support enters the digital world. Carers Central can provide free SIMS cards (with 6 months of free data, texts and calls), second hand devices and can loan out Amazon Fire tablets

### **Carers Week activities**

Carers Week is an opportunity to highlight the vital work that carers conduct and the support available to them. The team aimed to connect carers to all the support available including advice on money, access to wellbeing services and helping access learning and work. Carers Week 2020 included:

- Virtual Connections Coffee Morning (Carers Central)
  - Wellbeing while working during COVID-19 (Total Wellbeing)
  - Carers Central Q&A evening
  - Mindfulness during COVID-19 (Total Wellbeing Luton)
  - Support into learning and work (The Disability Resource Centre)
  - Caribbean Carers Virtual Group Meetup
  - Free online seated Yoga session (Carers Central)
- Carers Week 2021 Carers Central in conjunction with NHS England held two online events. These were both well attended. The topics included:
    - Code of conduct standard for carers
    - Carer contingency planning for emergencies
    - COVID-19 vaccine deployment programme for unpaid carers
    - How to get involved in future NHS developments

The Carer Support Officer, Levi Habashanti, had a Q&A slot on inspire 105.1FM Health and Fitness show. The station has 50,000 listeners per month. The session covered:

- How do you define a carer?
- What are the '10 ways we can help you in Carers Week 2021'?
- Can you tell us about the new Luton Carers' Handbook?
- What is a Carer's Assessment?
- Can I have a break from caring?
- What is an emergency plan?

Carers Central in conjunction with Luton Council also staffed a stand for the day in St George's Square, Luton, talking to carers and providing information.

### **Carers Rights Day**

A joint event with Carers Central and Total Legacy Care. Total Legacy Care (TLC) are a company providing legal advice and support to clients. TLC offer support with protecting people with wills, trusts, Lasting Powers of Attorney as well as probate services and funeral plans.

The main aim of the event was to make carers more aware of what services are out there to support them and how to enhance their own wellbeing.

### **Beds Cares Event**

Beds Cares! was a celebration of the informal carers in the community and a chance to discuss research ideas about carer wellbeing going into the future. The University of Bedfordshire invited all carers in the community: staff who are working carers, student carers and members of the public who are carers to come and join in.

Dr Emma Wilkinson & Dr Yannis Pappas (University of Bedfordshire) made contributions along with; Dr Jitka Vseteckova (Open University) & Prof Marie-Pierre Moreau (Anglia Ruskin University), Carers in Bedfordshire and The Disability Resource Centre.

Carers Central gave a presentation on the services that they provide to support adult carers in Luton.

### **Carers Panel**

A Carers Panel has been set up to work on the local carers' strategy in Luton. The participants include Luton Council, Carers Central, community groups and unpaid carers. The panel meets every two weeks to look at various themes. The Carers Panel vision is based around these themes:

- ✓ lead a 'good' everyday life
- ✓ feel recognised and supported in their caring role
- ✓ feel that their individual needs are met



- ✓ feel that their experiences are being learned from and built on
- ✓ feel valued for their caring role
- ✓ where appropriate, have an equal voice in planning the care and support of the person they cared for

### **Carers Pathway / Carers Lounge**

Carers Central work in partnership with the Luton and Dunstable Hospital and Carers in Bedfordshire to ensure that carers visiting the hospital and patients staying at the wards can learn about the support that is available, particularly important whilst the Carers Lounge onsite has been closed. Clear messaging for support has been provided including working with PALs, discharge teams and ward staff. These are available as live sessions or pre-recorded YouTube videos.

## Impact on carers – Making a Difference

The support provided to carers through the pandemic can be demonstrated with the following of case studies, which highlight the difference this support has made to carers:

Carer A became the main carer for his mum overnight as his dad passed away suddenly. Carer A's mum has been suffering from dementia for over 10 years. Carer A was unable to cope with his new caring role because previously his dad did everything. His mum is unable to support herself and needs constant supervision and support. Carer A is new to the caring role and had no idea what support his mum needs or what is available to him.

Carers Central for a Carers Assessment with Luton Council referred Carer A to accept the free respite sitting service, to get some time for himself. They were also referred to Adult Social Services for his mum to have a needs assessment, regarding everyday needs.

Carer A was able to get a better understanding of what support was out there for. Carer A was supported to deal with his caring role.

Carer B rang to make us aware that he was not coping with his caring role and felt isolated; he had been trying to get hold of the GP but was unable to do so. He felt that he was unable to cope with his current situation without the right support. He had been given medication for depression, but they were about to run out and he could not contact the GP to get a repeat prescription.

The Carers Central Carer Support Worker contacted the Link Worker at the carer's GP surgery and made aware of the situation and the support this person needed. The person was contacted on the same day and supported to get a repeat prescription. They were also supported to access a counselling service attached to their surgery.

This has allowed them to continue with his caring role with less stress and anxiety.

Carer C has been incredibly stressed about her dad being in a care home while in lockdown. The lady expressed that she was not able to see her dad for over 4 months due to COVID restrictions in the home. The client also made the Carer Support Worker aware that her dad did not have his own wheelchair and was often unable to leave their bed.

Carer C was referred to local agencies to look at what measures were in place within the home and was supported to obtain a wheelchair for their dad and a wellbeing action plan devised.

The carer now feels less stressed and feels assured their father is now able to get out of bed and move around. There is regular contact with the care home regarding COVID arrangements for contact with their father.

The carer also recognises the importance of their own wellbeing,

Carer D was very distressed at the fact they had not seen their loved ones for over 8 months due to coronavirus restrictions. The family member lives in a care home permanently and required a wheelchair.

Carer D was supported to talk to a Healthwatch representative in the carer's drop-in meeting. The Carer Support Worker also looked at wellbeing of the carer and how taking time out from the caring role is important, over several sessions.

Healthwatch supported Carer D to get a wheelchair for her family member which meant they could have a better quality of life and get about a bit more. The COVID-19 restrictions remained in place but arrangements were made to enable Carer D to see her family member.

Carer D is also a carer for her mum and felt that they support she got from Carers Central and Healthwatch allowed her to carry out her caring role more effectively. She was able to concentrate on providing better care to her mum who is also bed bound and lives by herself. She no longer feels like she must be in two places at once and that there was not enough time in the day and takes more notice her own wellbeing and take some time for herself.

The carer still attends weekly Carers Central coffee morning meetings to get support regarding ongoing carer issues and take part in online Yoga.

Mr E is 70 years old and has COPD. He is still working part time, but this is becoming increasingly difficult. His wife called to see what their options are as she is now doing a lot of his personal care. He is claiming his state pension and has a small salary.

Mrs E is also retired and is now struggling to look after her husband. Mr E was suddenly admitted to hospital. Once he was released, he decided to give up his part time job.

Carers Central discussed with Mr and Mrs E the benefits available to them, such as Attendance Allowance and Carer's Allowance and helped them complete the relevant forms and they were awarded the benefit.

A Needs Assessment and Carer's Assessment with Luton Council was arranged. This was conducted over the phone, and they received the specific equipment. This was a great help to both Mr and Mrs E.

This has all been a great help to Mrs E. She feels more in control of their situation and welcomes the support. A referral to Total Wellbeing for talking therapy was made to provide additional support. She is also doing an online exercise class and Carers Central are making a monthly welfare telephone call to Mr E.

Carer F has returned to the UK from Australia where she has lived for the last 20 years. She has returned to look after her elderly father who has multiple health issues. Carer F was feeling a bit overwhelmed and disorientated by the COVID situation and was very tearful.

Carers Central discussed with Carer F the benefits that may be available to her and her father as they are not receiving anything other than his state pension. Unfortunately, Carer F is unable to claim Carers Allowance until she has lived back in the country for 2 years. They were assisted to apply for Attendance Allowance and a Blue Badge and referred her to Luton Council Adult Social Services to conduct a Needs Assessment.

Carer F's father is now in receipt of Attendance Allowance and his Blue Badge. The Blue Badge will be extremely helpful as he is a wheelchair user and Carer F found it difficult to transport him to appointments. Carers Central maintain contact with the carer on a regular basis to offer support.

Carer J is 83 years old and is the sole carer for his wife who is 80 years old. They have no family and have both been shielding. During the pandemic they have been relying on a neighbour to bring them shopping and medication. Carer J's wife has arthritis and a heart condition. They were referred to Carers Central by Total Wellbeing.

Carers Central contacted Carer J via telephone. He was very tired and wanted some respite. Carers Central were able to support in several ways including referrals to: Luton Council Adult Social Services for a Carer's Assessment and for his wife to also receive a Needs Assessment, Total Wellbeing for talking therapies, Lifeline arranged for a key safe to be installed, GP to discuss the concerns around his mental health, Age Concern for a cleaner and given the details for Morrison's Doorstep Delivery. Information was also provided on implementing a sitting service and contingency plan.

Carer K came to the Carers Central with several concerns as an unpaid carer. Carer K's mum was the main carer for their dad, who passed away due to Covid-19. As a result, the client's mother, who also has several medical conditions, due to safeguarding and safety concerns, it was considered best if the client's mum moved into the client's house with his brother.

Carer K was supported to request a risk assessment for his mum; Carer K's mum also has mental health issues due to the death of her husband; this also had an impact on the client and his brother. Carer K was supported to request support and therapies for his mum, brother, and himself. Client was also supported to obtain a Carer's Assessment to look at his wellbeing needs regarding his caring role.

Carer K's mum has been assessed and support is being put in place to help her with everyday needs. Carer K's mum and brother's wellbeing is being supported regarding their sudden loss. Carer K is being supported to look at his caring needs and his own wellbeing.

Carer L is 75 years old and looks after her husband. He had a stroke four years ago. He has been mobile but because of the pandemic his mobility has now deteriorated due to lack of exercise. Carer L receives no help or support.

After a telephone discussion with Carer L, Carers Central requested a Needs Assessment, OT Assessment and Carer's Assessment.

Carers Central provide regular welfare calls to Carer L to offer support and explore any wider needs.

Carer L is now able to take time to meet friends knowing her husband has been looked after.

Carer M was being supported by her husband as her full-time carer, as she was diagnosed with cancer (now in remission), in recent months Carer M has now become the main carer for her husband who has been critically ill and admitted into hospital.

Carer M was advised regarding benefits that her husband would be able to apply for and what evidence they will need to support the application.

Carer M was given information regarding an OT assessment and how to access incontinence services.

Carer M has been supported to apply for Attendance Allowance and an Occupational Therapist has come out to do an assessment on her husband, who may need to be relocated downstairs due to his medical condition.

Carer N is 55 years old and looks after her husband. He has dementia. She has just taken early retirement as she was finding it exceedingly difficult to look after her husband and work fulltime.

After a telephone discussion with Carer N, Carers Central requested a Needs and Carer's Assessment.

Carers Central call Mrs F on a regular basis to offer support and have helped completing benefit forms for Personal Independence Payment and Carer's Allowance which has been successful.

Carer N and the person they care for have been assessed and appropriate support has been in place.

Regular contact with Carer N ensures that ongoing support is monitored and provided when necessary.

Carer Q has been the guardian for her autistic grandson for 15 years. He also has mobility problems that has meant he has had three operations on his hip. He will be turning 18 soon and Carer Q needs support on what happens next.

Support was given to help her apply for PIP (Personal Independence Payment) for her grandson. They were also helped to look supported living.

Carer Q had never registered with her GP as her grandson's main carer. She registered and this meant that she became eligible for the Covid vaccine earlier. The PIP (Personal Independence Payment) application has successfully been awarded providing more independence, choice, and control.

The Carers Central Carers Survey 2022 provided the following insights to the support available and its impact.

Carers access support across a range of interventions, with over 50% accessing information and advice, 26% wellbeing support, 22% accessing COVID-19 information, 26% requiring services for their cared for. Despite the initially hesitancy to access online information, 18% access online learning opportunities. See Appendix 2.

Carers indicated that access to services has positively impacted their life. Carers reporting having better access to information and advice, improved emotional wellbeing, increased confidence and better choice and control, and were able to make more informed decisions. This is demonstrated in the survey results in Appendix 2. Feedback from carers can also be found in the quotes provided in Appendix 4.



## Evaluation

Support organisations have played a vital role in providing somewhere to turn for unpaid carers who have been significantly impacted by the pandemic.

The findings of this report show that carers have been negatively impacted by:

- isolation
- reduced support networks
- poor mental health and overall wellbeing
- lack of access to health services
- limited access to respite
- exhaustion
- lack of access to statutory services

Having somewhere to turn and get trusted information and practical support has played a pivotal role, and some stability, during a time of unprecedented change and uncertainty.

Services were challenged by the lockdowns and have amazingly kept services operational by quickly developing services to be delivered remotely. This included delivering online sessions, increasing the methods of communication and the further development of self-help resources. Services have become more agile and remained operational throughout the pandemic, adjusting their services to meet the needs of carers.

Carers benefited from a range of services such as the carers support organisation (Carers Central) and those providing condition specific support agencies such as Tibbs, Alzheimer's Society and YAWN life. Welfare calls to carers and access to up to date and validated information proved invaluable.

Key messages were delivered to carers through a multimedia approach on topics including national government guidance, COVID-19 information, access to PPE, testing, and vaccinations. Carers have been supported to access the support that they need, including benefits advice, equipment, and wellbeing support. All having a demonstrated positive impact to physical, mental, and financial wellbeing.

Carers felt less alone, better informed, and more confident in their role.

## Recommendations and next steps

The pandemic has had a significant impact on carers and the ways that they have been supported. The impact on carers and cared for people is still being felt, with delayed operations and hospital admissions, increased waiting lists for services and telephone appointments with GPs.

However, there are some lessons learnt and positive outcomes from the pandemic outlined in the report that can have a lasting impact and can be used to shape services moving forward. This includes:

- Increase methods of communication in a way and at a time that best suits carers
- Providing carers with a voice within their individual circumstance and wider settings, such as helping to shape services for the future
- Stakeholders working collaboratively to support carers including the local authorities, CCG (Clinical Commissioning Group), Primary Care Network and Public Health
- Working across geographical boundaries to provide parity of service such as the work across Bedfordshire, Luton, and Milton Keynes (BLMK)
- Holistic support, providing a range of solutions to the practical, financial, and emotional needs of carers, the cared for person and family members
- Reducing isolation by providing opportunities to connect on and offline
- Highlighting the vital work that carers carry out every day

Carers have been the backbone of care within the home to the most vulnerable of residents. Carers often work in isolation, with limited support and at considerable expense to their mental and physical health. The pandemic has shone a light on all their challenging work with a renewed appreciation for the vital role carers play in our communities. It is vital that we continue to care for carers and support them to be confident in their role, whilst also looking after themselves to help them have their own fulfilled and meaningful life.

## **Bibliography**

1 [Valuing Carers 2015](#) – The rising value of carers' support is the third in a series of research reports looking at the value to the UK economy of the support provided by unpaid carers.

This report is authored by Professor Sue Yeandle (University of Sheffield) and Dr Lisa Buckner (University of Leeds) and published by Carers UK.

2 Luton Council Carers Strategy (referencing the 2011 Census)

3 [Facts about Carers, 2019 Carers UK](#)

4 [Caring Behind Closed Doors – Six Months on, Carers UK](#)

5 [State of Caring 2021, Carers UK](#)

6 ['How are you doing' carers survey 2020 – 2021 – Healthwatch Luton](#)

7 Carers Central Carers Survey 2022

## Appendix 1

### Carers Central Model

#### Stage 1 Carers Hub (Contact Centre)

The hub is set-up to provide multiple channels and points of entry to access the service. It provides timely and easy access to information, advice and signposting to further information and services.



**Website - [www.carerscentral.org.uk](http://www.carerscentral.org.uk)**

A dedicated accessible website provides 24/7 information including emergency numbers, service offer, details on events, self-help resources and webchat.

**Emails - [carerscentral@drcbeds.org.uk](mailto:carerscentral@drcbeds.org.uk)**

**Helpline - 0300 303 0201**

## **Online sessions**

Dedicated online meeting rooms are available for group and one-to-one support whether this be for a coffee morning or visiting speakers from wider support organisations or peer support groups. With changing restrictions throughout the pandemic, these online sessions provided a safe space to connect.

Carers can also access over 50 online learning modules including wellbeing, emotional resilience, care skills training and employment support. Modules covering healthy lifestyles include:

- ✓ Building confidence
- ✓ Finding balance
- ✓ Making positive changes
- ✓ Loving yourself
- ✓ Feeling fit
- ✓ Managing relationships
- ✓ Transition
- ✓ Resilience
- ✓ Good sleep

## **Face-to-face**

Carers can access Carers Central by visiting our centres or via any of our outreach activities including:

- One-to-one appointments
- Carers Cafe
- Workshops
- Community events/drop-ins

These remain COVID-19 secure with access to PPE.

## **Referrals**

Carers can self-refer or be referred from internal services, partner organisations and professionals. This includes a range of statutory, condition specific, and local VCS (voluntary and community services). This centralised approach tailored to the needs of the carer as well as the carers for person.

## Hub

Key features of Carers Central include:

- ✓ rapid early intervention
- ✓ web portal for self-help information and self-referral
- ✓ a referral point for professionals
- ✓ web-based management system tracks all contacts
- ✓ triage at initial contact and resolution of less complex situations
- ✓ inward and outward referrals
- ✓ appointment booking with specialist advisors

The carer's individual situation (enquiry) is input to a Case Management System (CMS), unless they do not wish, ensuring that they tell their story once, preventing frustrations faced by carers having to repeat conversations to multiple agencies. Contacts and actions are recorded on an electronic record with carer details and service/network interventions, which can create a secure electronic system referral to teams and partners.

Triage determines the different topics that require intervention (and their urgency) and identifies levels of support needed. At this point the Information Assistant will either:

- provide the required advice
- book an appointment with specialist team members e.g. benefits advice and form filling support
- refer directly to partner organisations
- refer to the Carer Support Workers for assessment and emotional and practical support

## Stage 2 case management

Assisted by Carer Support Workers, case management includes:

- carers rights
- carers need assessment
- emergency plans
- wellbeing action planning
- refer to wider services and/or partners
- council referrals including Carer's Assessments and breaks
- respite and day services/activities

Support continues throughout with various interventions including GP health checks, registration as a carer and wellbeing activities.

## **Partner case management**

Working with network partners to provide specialist services that best meet the needs of carers.

## **Stage 3 – Interventions**

Carers access the range of services and activities as outlined in the specification. Services are also available for the 'cared for' person including provision whilst carers access support sessions.

### **Adult carer support includes:**

- Peer support groups include Carers Eating Disorder Association, Physical Health and Emotional Wellbeing, carers for those with addiction and expanded into other cohorts
- Visiting speakers, workshops and presentations include EFLT, BDAP (Bedfordshire Domestic Abuse Partnership), and end of life support (NHSE (NHS England))
- Care Academy provides care skills training through live, online learning sessions and videos for the Care Certificate and condition-specific workshops
- Disability equipment and everyday living aids hosted in the equipment store with access to Trusted Assessors
- Employment support recognises caring commitments and provides employment solutions by members of the Institute of Employability Professionals
- Services for employers' advice on best practice and the Care Act 2014, supported with implementations of carers' policies, 'Carer Champions' and commitment from a business with a legal and moral perspective
- Community and adult learning opportunities
- Money management service with topics including Power of Attorney, wills, and probate, managing income and expenditure, practical solutions, and lasting behavioural changes
- Benefits advice including benefits checks, applications and appeals including Carer's Allowance and Personal Independence Payments for the cared for person
- Support with volunteering opportunities including peer support within the service
- Health and wellbeing support outlined further in the application include over 25 topics including emotional resilience, finding balance, stress and change management
- Fitness support including access to live and pre-recorded video (tablets and equipment provided) lessons



- Wider DRC services including Direct Payments, Advice Central and disability advice services and linking to partners including activities and opportunities for social contact

Other support includes.

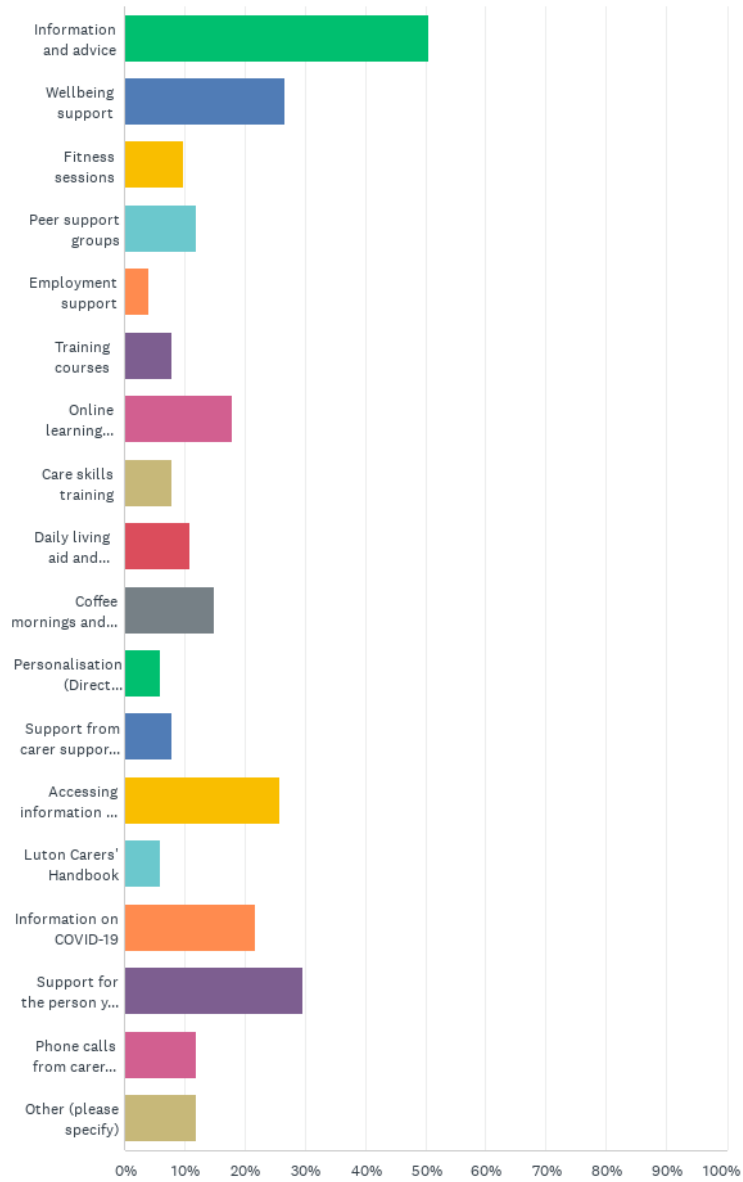
- ✓ Online or live bespoke exercise sessions
- ✓ 50 YouTube fitness sessions
- ✓ Wellbeing calls to ensure those that are most isolated are not left vulnerable
- ✓ Accessing a range of other services including peer-led groups, carers' cafes, and carers breaks
- ✓ Regular newsletters including "What's On" listings and news from partners
- ✓ Specialist sessions including Emotional Wellbeing
- ✓ External services and activities

Information sheets and the Luton Carers' Handbook are also available. Content includes Carer's Assessments, carers' breaks, benefits and money, end of life care, bereavement, carers' support, wellbeing, and useful contact numbers.

A regular newsletter includes up-to-date information, services for carers, events, links to further information and partners.

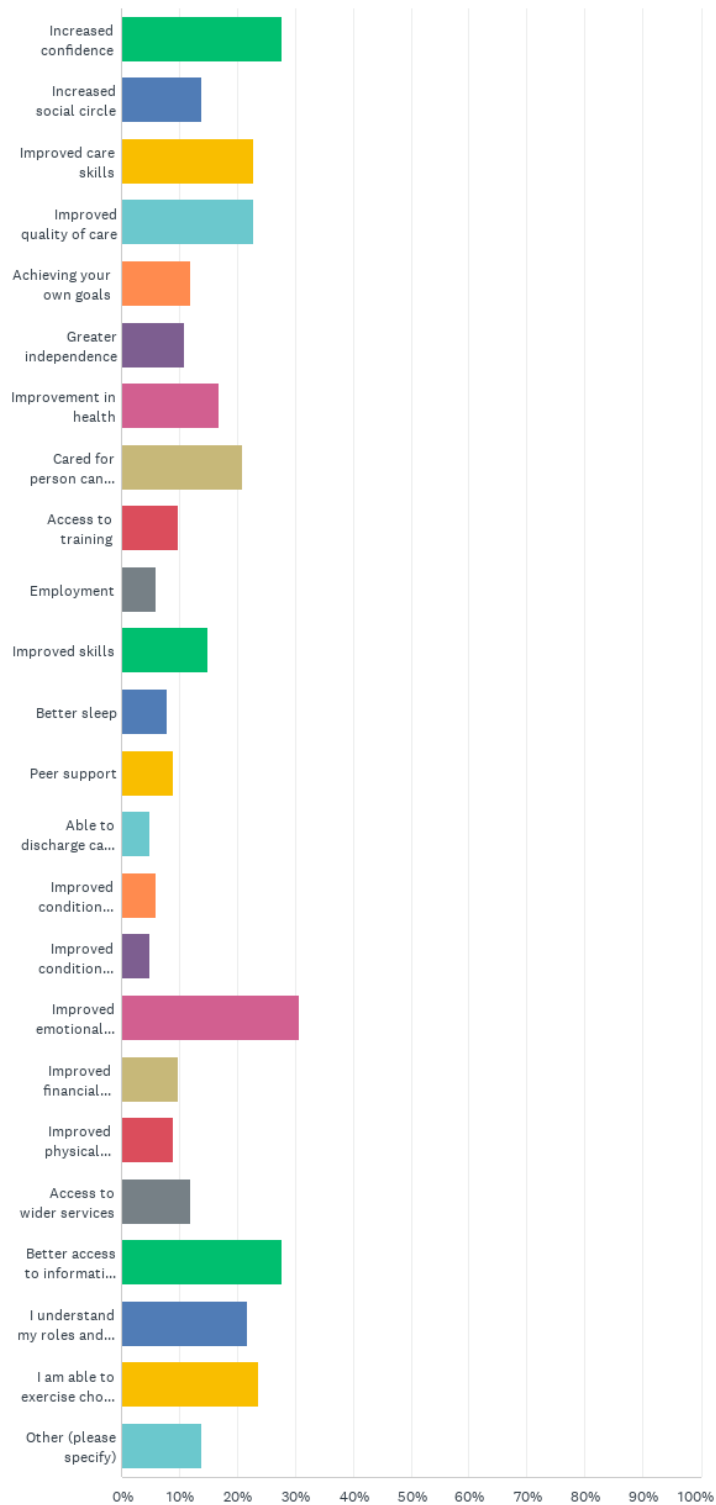
## Appendix 2

Q4 There are a number of support services available for carers. Which carer support services do you access?



### Appendix 3

Q6 What impact has this support had on your everyday life?



## Appendix 4

Quotes below are from carers from the Carers Central Carers Survey 2022, when asked about the impact of accessing services:

- The phone calls were helpful, and it was nice to speak to someone as I felt like I have been rather neglected during the pandemic.
- Information provided was helpful and easy to understand. Where help could not be provided directly, I was signposted to the relevant areas where support could be found.
- Allowed my Nanny to stay at home when I thought she was going to have to go into a home. Seems much brighter in her personality, healthier.
- Useful advice in the system.
- It has made me see I am not alone, and I can do it.
- It reassured me that I was doing the right thing and gave advice
- If I ever had a question, I could usually find the information I needed which resulted in informed decision making.
- Gave cognitive behavioural support skills for managing worries
- Help with equipment and physio support
- Really increased my confidence
- Support when needed it
- GPs we are not great obviously it helped with my mental well-being at the time but there is never any follow-on support or after care to check how you're getting on and majority now you apply for yourself whereas years ago a doctor would refer you with a note etc so the person on the other end could get some idea of your issues
- It enabled me to have a set time that was mine, to unwind and focus on myself instead of my caring duties
- Information is my problem. Plenty of folk talk about stuff but finding out what is correct is another matter. A fair bit of the time the professionals do not know so you end up having to research stuff yourself and then get them to take it on board.
- More informed
- Did not feel so alone
- Learned what help was available, both financially and practically.
- I was given peace of mind.
- Lots of information
- Helpful to know I am not alone
- Respite
- Someone to talk to
- Gave us the support we needed

- Lots of support from multiple sources
- Confirmed my approach.
- It answered the questions I had
- Someone to share my feelings who knows what I am talking about
- Could look up in my own time
- It helped me become a better person for myself but also the people around me.
- Good info
- Helped through a tough time, ensuring people who used it were not feeling alone.
- Helped to bring people together
- Getting the support needed
- It is just good and helpful to be able to talk to somebody who understands
- Gave me more confidence and motivation to wake up every day and feel good.
- It did the job.
- Life is easier
- Got good access to follow up information.
- They really helped me to improve my mental health
- Services I used to help me gain my confidence back and help me get more of an understanding with my job. Helping others during the pandemic was hard as I was also looking after myself, but after using these service's it helped me figure things out
- They help me progress with my goals.
- There was a lot of useful information which I previously was not aware of, plus the chance to meet other people in a similar situation who I could talk to.
- Kept me well informed and able to make required decisions to move forward when I had been unsure.
- It gave me understanding that I am not the only one going through it and that others are experiencing the same issues.
- People were kind and helpful they
- Time away from the person I care for
- Helps me understand what is needed
- Helped me get more information about Covid-19
- We have had no help my husband is my carer and has had no support
- Not able to access all your equipment to enable my mother to drink/eat very well but what I could obtain did help a little
- Knowing I am doing things right and getting extra help.
- Introduced me to one session for carer and cared for.
- Easily accessible

- The direct payments are much better. I get lots of help from our care assistants and can now have a little bit of a life for myself.
- I appreciated the phone calls from Sally, very thoughtful.
- Comprehensive service
- Blind Veterans are the very best on all counts when caring for someone who is blind/ disabled. I have yet to find another support group with such a wide knowledge in supporting cared for and carer.
- Services help the cared for person not always the carer
- Tibbs are very supportive Always available
- The Disability Resource Centre and Alzheimer's society provided support and advice
- I had a good network of support around me
- It helped me to care for my mum
- Kept my mind busy on something other than covid
- I felt like I was no longer alone, and I felt taken care of, with care by Levi
- Was able to email for help
- Talking to someone
- Gave good clear advice and information.
- Nice people helped me.
- Got extra support in the home environment
- I received support from the career centre to secure DLA (Disability Living Allowance) payments for my child and I received CAMHS support to get a medical diagnosis and treatment for my child. I was put on an NVR course to help me manage caring for my child. I also got support at a EHCP tribunal.
- It was helpful as I did not know where to get the help before DRC helped us
- The support available from YAWN Life has been amazing though the whole pandemic. They have been open whereas other services stopped. They provided daily contact by phone or Zoom during initial 3-month lockdown. They were a great source of information and advice and relieved anxiety for me and son. Providing easy read or easy explanation. they made lots of changes and encouraged everyone to be safe wear mask etc. Support son to test and kept everyone safe but keep their friends and social contact.
- I can get out. And have me time with sit in service for my husband which allows me to be me for a while
- There was information available when I needed it with regular emails
- Knowing there was somewhere to turn to
- I finally got carers allowance after 6 months.
- My husband has support which allows me to work. His PA (Personal Assistant) can help my husband's behaviour which makes life better at home for myself and our son.
- I stopped feeling helpless and found I was doing better than I thought

- The knowledge that there was someone available at the end of the phone.

