JOINT CARERS STRATEGY REFRESH 2022-2025 Recognising, Valuing and Supporting Carers in Leicester, Leicestershire and Rutland



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1. Foreword

The COVID-19 pandemic has been a challenging time for everyone. While many people have played an important role enabling others to cope with those challenges, it is especially important to recognise all those people who look after someone who couldn't manage without their support. Carers play an essential role in our communities, often without recognition of the commitments they make and the substantial impact that their selfless commitment to others can have on their own wellbeing. We would like to express our thanks to carers across Leicester, Leicestershire & Rutland and publicly recognise the outstanding contribution they make to our communities.

We have heard carers tell us how they can feel isolated, that they may experience higher levels of strain on their own physical health and wellbeing, and that they often feel worried about what the future holds since the pandemic. We have been mindful of this when setting the priorities detailed in the refreshed strategy. Central to this is that carers have told us that they want to have opportunities to live their own life alongside their caring role. We have listened to what they have said to us. We want to ensure that carers across Leicester, Leicestershire & Rutland have access to services that support their physical and mental health and promote their wellbeing. One important element of this is identifying carers early and ensuring that the right support is accessible in the right places and at the right time for all carers.

We recognise that in order to achieve this vision and the best possible outcomes for carers, NHS and local authority partners need to work collaboratively. We therefore publish our strategy jointly as a sign of how we intend to work together. With our minds now set firmly on 'recovery' and living with COVID, this refreshed strategy reflects our ongoing commitment to carers. We look forward to seeing the implementation of the plans within the strategy over the next five years and being part of a system that ensures carers are not only recognised but are valued and supported to live healthy and fulfilled lives.

2. Carers Foreword

Dave T. Local carer

I'm delighted to have been asked to write this foreword. Cards on the table. I don't think carers were particularly well served in the past and I'm not sure they are now. I could go on about that, but I won't. Why? Because I think it's changing, in fact I know it is, and I know the desire to improve is coming from providers as well as carers. A glimpse of this is a carer's voice being heard here right at the beginning.

What is a carer and why do they need a strategy? With one in four adults becoming a carer during the pandemic (and already we're ignoring the vast number of young carers) the idea that there will be a simple definition is wishful thinking. What connects me (a working carer) with a young carer, with a parent carer, with a young adult carer? Well, there is someone who couldn't cope with their everyday life without my help, without our help. Doesn't much matter who or how, there is someone who we have a commitment to support. We are part of the team (us, medical, domiciliary care, social work) that works together to help someone live their life.

And that's where this strategy could, and should, and will if we follow it, take us. A team. Working together. Agencies communicating with each other, carers in that loop. Carers being treated the same way as professionals, informed, included, supported. Good employment practice extended to include all the care team members, to include carers.

As well as treating carers as part of the team there's another job for you professionals. You need to tell us that what we're doing has a name. Carers rarely define themselves as 'a carer' we're sons, daughters, parents, friends, and that's how we see ourselves. 'Carer' is a label not an identity. The thing is, if I don't think to call what I do 'caring' then I'm unlikely to know there's an Act that grants me rights; that there's a dedicated support service for me; that there are people who will help me. 'Carers' don't know this. We really don't. If you tip us the nod you can make our lives so much better and that's got to be worth your effort.

Sounds like a plan? We all want the same thing. The best possible life for the person we're supporting without burning ourselves out.

Here's how we do it...

Voice of local young carers

For us the strategy means that someone recognises what we do, how we feel and how we struggle.

It's a start in being supported as a young carer and being given time out to think about my emotional wellbeing as I suffer, as I'm isolated more than my friends.

It's important that everyone who is involved with young carers sees the strategy, especially schools. We spend so much time in school it would be great if this strategy brings change. We'd like to see every school having a named person who is the link person for the young carers, someone who understand us more, who understands the reasons we miss deadlines or are late to school. The strategy will hopefully affect the things that matter to us and allow us to talk about our worries and our good parts of life.

3. Who is the Strategy for?

'We would describe a carer as anyone who supports and cares, unpaid, for a family member or friend living with a disability, long-term illness, substance misuse or a mental health need, who would not manage without their help.'

One of the biggest challenges in developing a strategy for carers, is that there are many definitions that apply, including within various national policy and legislation documents. Comments provided to us by carers across Leicester, Leicestershire and Rutland have suggested that the following factors are important to acknowledge explicitly:

- That a carer does not always live with the person they care for.
- That a caring role should not be defined by the number of hours they provide care.
- That the carer could be caring for their son, daughter, husband, wife, mother or father, but that this list is not exhaustive, and the relationship between the carer and the person may also extend beyond traditional family roles.
- Sometimes a carer can be caring for more than one person, across differing generations.
- Carers may also receive support from a carer themselves because of their own illness or disability.
- Receipt of a carers allowance does not mean that they are in a paid carer role.
- The carer can be any age; adult carer over the age of 18, parent carer who provides care to a child or an adult, young carers under the age of 18 and young adult carers who are aged between 18 and 25 years.
- There may be more than one carer caring for the same person
- The need of the person they care for may not be visible.

It is recognised that some people do not relate to the term 'carer' however, for the purpose of this strategy this will be the term used to capture the diverse nature of the caring role.

4. Profile of carers in Leicester, Leicestershire and Rutland

Census data from 2011 told us that there are over 105,000 carers across Leicester Leicestershire and Rutland (LLR). Nearly 2000 of the 105,000 (2%) LLR carers were aged between 0-15 years, and 203 of these young carers provide 50 or more hours of unpaid care per week. Overall, 67% of carers provide care for 1-19hrs a week. 57% of LLR carers are female, the highest provision of care for both sexes is provided by those aged 25-64.

There is no doubt that the COVID-19 pandemic has significantly increased the numbers of people that now find themselves in a caring role, but we are waiting for the results from the Census undertaken in 2021to be able to provide more detailed information on the gender split of our caring population, the ethnic breakdown, the age and number of hours spent caring as provided in the last strategy. We have been advised by the Office of National Statistics that this information should be released between December 2022 and January 2023 and will update this section, once the information is available.

5. National Policy and Legislation



This carers strategy works to support the aims of the Government as highlighted within these national policy and legislative documents.

6. Our local vision for Carers

'Carers, of all ages across Leicester, Leicestershire and Rutland will be identified early, and feel valued and respected. They will be offered appropriate support wherever possible to enable them to continue their caring role and maintain their own health and wellbeing'.

This strategy has been refreshed to reflect the accomplishments of the previous strategy such as:

- Launching a Leicester, Leicestershire and Rutland carers passport.
- The incorporation of quality markers in GP surgeries.
- Staff training around carer awareness within a number of health and social care organisations.
- A review of the information and advice available to carers with necessary updates.
- Larger numbers of carers registering with their GPs.
- A new regional carer co-production group.

The refreshed strategy builds on existing actions and represents the voice of local carers across Leicester, Leicestershire and Rutland, particularly following the COVID-19 pandemic. It also sits alongside other local plans, such as the Health and Wellbeing Strategies for Leicester, Leicestershire & Rutland 2022-2032 and Social Care Strategies for Adults and Children's Services across Leicester City & Leicestershire and Rutland County Council's. Ongoing challenges such as continuing to raise awareness of carer issues, promoting the early identification of carers, and continuing to keep information up to date remain embedded within the priorities of the refreshed strategy.

In July 2022, integrated care systems were established across England. Integrated care is about joining up the care provided by different organisations and services. It's about giving people the support they need, joined up across local councils, the NHS and other partners. Our integrated care system covers Leicester, Leicestershire & Rutland.

The Leicester, Leicestershire & Rutland Integrated Care System has two statutory bodies.

- 1) Leicester, Leicestershire and Rutland Health and Wellbeing Partnership, responsible for producing an integrated care strategy on how to meet the health and wellbeing needs of the population and,
- 2) Leicester, Leicestershire and Rutland Integrated Care Board, the statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging the provision of health services in their area. The Integrated Care Board replace what were once known as clinical commissioning groups.

In order to avoid the Integrated Care System losing sight of issues affecting local areas, other groups called place-based partnerships and provider collaboratives are in place.

The group that is responsible for highlighting the needs of carers, development and delivery of this strategy across the Integrated Care System is the Leicester, Leicestershire & Rutland Carers Delivery group which is made up of representatives from the following organisations:

- Leicester City Council,
- Leicestershire County Council
- Rutland County Council, (all responsible for social care),
- Leicester, Leicestershire & Rutland Integrated Care Board who work alongside GP surgeries,
- Leicestershire Partnership NHS Trust,
- · University Hospitals of Leicester,
- Voluntary and community sector organisations (notably those organisations delivering carer support services and representing the voice of the carers they support)
- Healthwatch

The organisations that are part of the Leicester, Leicestershire & Rutland Carers Delivery Group have signed up to this strategy and have committed to work together to deliver our local vision for carers.

7. The impact of the COVID-19 pandemic

No one could have anticipated that during the life of the 2018-2021 strategy, there would be a pandemic that would have such a monumental impact on carers' lives. As a nation we are moving to recovery and living safely with Covid but for carers there are lasting effects on many areas of their lives: their mental and physical health, employment and finances, their emotional wellbeing, with many taking on a new role as a carer.

Increase in carer numbers

Carers UK estimate that an additional 4.5 million people became carers overnight, in March 2020 which equates to 1 in 4 UK adults providing care to an older, disabled or ill relative or friend at the height of the pandemic. If we apply this across Leicester, Leicestershire and Rutland this suggests there would be around 220,000 adult carers.

We acknowledge this increase and prioritise carer identification

Loneliness

Carers had already told us they experience feelings of loneliness; and Carers UK research shows that the number of carers feeling isolated doubled from 2020-2021 from 9% to 18%. This was also echoed by carers locally. Those feelings increased because of physical distancing and shielding, the closure of community services, unemployment, and the loss of loved ones which subsequently affected the mental well-being and resilience of the caring community.

Prior to the pandemic, young carers were already an under-identified and under-recognised group. The closure of schools, universities and other educational settings during the pandemic meant that many young carers lost regular forms of contact, increasing the invisibility of young carers.

We acknowledge and prioritise the need for carers to have a life alongside caring

Providing more care

According to Carers Trust, 58% of young carers are caring for longer since Coronavirus and are spending on average ten hours a week more on their caring responsibilities. Among young adult carers the proportion is even higher at 63.6%. A Carers UK report released in October 2020 states that 81% of carers reported they were providing more care since the start of the outbreak for one or more of the following reasons:

- The needs of the person they care for have increased.
- That local services reduced their offer or closed altogether.
- Someone they rely on for breaks was no longer available.
- They were worried about paid health and social care staff having contact with the person they care for.

As a result of this, 72% of carers have not had any breaks throughout the pandemic.

We acknowledge the need for carers to have a break from caring and prioritise actions to support this

Financial Impact

Carer's UK State of Caring report 2021, stated that 36% of carers said their financial situation had got worse since the start of the pandemic, largely due to people being at home more, using more energy, being unable to work either due to being furloughed or as a result of the increase in care they were providing. Locally, carers have also highlighted these challenges, and this remains an area of concern as they also tackle the cost of living and fuel crises. Caring households are significantly more likely to have had difficulty paying for at least one type of living expense since the beginning of the pandemic compared to non-caring households.

We acknowledge and prioritise the need for carers to have appropriate advice around their financial circumstances

Sortified The East Midlands' Unpaid Key Workers: Supporting Unpaid Carers by adapting services and responding to need during the COVID-19 crisis

The East Midlands Association of Directors of Social Services (EM ADASS) recognised the impact of the pandemic on carers and commissioned a community interest company called Sortified to work with local carers to establish a simple list of recommendations for councils, based on their experiences of the pandemic. The subsequent report outlined areas where carers required support both on an immediate and long-term basis. As we are now learning to live with COVID-19 some of the immediate concerns presented in the report are now resolved, however those that remain, have been built into our priorities within this strategy. The full report can be found at: East Midlands Carers — Sortified

8. What Leicester, Leicestershire and Rutland Carers say –

situations. The carers were from a range of backgrounds including parent carers, carers of different ethnic origins, young carers, older carers and working carers. Children's carer support is better serviced This is what they told us. The term "Carer doesn't cover enough but when they leave school and education of how much care we provide " stops, you are not provisioned with support to fill their days The passport has been a runaway success Carers often appear invisible to the general population Pic of carer I find that I spend a lot of time sorting things for the person we look after and put myself last! I attend all medical appointments with the family member I care for and since the start of the pandemic, and with his permission "Carer's shouldn't have to keep repeating converse with the GP on telephone their wishes/the cared for person's appointments. challenges. This happens an awful lot and can be upsetting for the carer having to go Respite Respite Respite over the same information several times. You know all this so I spent hours on the phone trying to let's now tackle it organise my dad's hospital instead of asking the discharge, far easier for them to call questions that we already know the It's good when somebody bothers about you answer to. Need as a carer, that you are identified as a carer action NOW

During the summer of 2021 we tried to speak to as many local carers as we could about the 2018-2021 Carers Strategy and their caring

Organisations that are responsible for delivering upon this strategy are committed to ensuring that the carer voice continues to be heard. The ambition is to move towards a co-productive approach to developing delivery plans that value carers and their lived experiences.

9. Guiding Principles



The strategy continues to be underpinned by the guiding principles that reflect both the national and local requirements of carers.

The above principles have been translated into key priorities and actions (as detailed in section 9) and each member of the Leicester, Leicestershire and Rutland Carers Delivery Group will be expected to build upon them in the development of their delivery plans. Progress on those plans will then be collated and fed into wider integrated care system priorities.

Although funding in relation to carers is not directly addressed within this strategy, the financial position faced by both health and social care organisations cannot be ignored. This might seem like the Strategy lacks detail in some areas however, the available resources for each organisation will be reflected in the plans that will be developed by partners.

10. Key priorities and associated actions

What the engagement told us	What will we carry forward	What are our new actions
Identification is still an issue for carers, linked to lack of understanding of what caring is. Engagement recognised the need for GP surgeries to improve identification of carers. Lack of recognition was cited as a barrier to being kept informed; this was mentioned as a particular issue in hospital settings. Carers not receiving Carers Allowance feel they aren't recognised like those who receive it.	Ongoing staff training development to aid awareness and identification. Ongoing review of information and use of pages to aid carers to identify themselves and support staff to identify them. Continued promotion of Digital Resource for Carers & Employers for Carers resources.	Continued promotion and growth of the Carers Passport scheme, particularly in hospital settings. Improving access to primary care and health checks for carers as a means of supporting carers to maintain their own physical and mental health and wellbeing particularly for working carers and parent carers. A social seeding programme to provide ongoing relationships and alliances through the Integrated Care System and ensure it is reaching out to carers across cultures. Ensure better carer identification and consideration of their needs on admission to and discharge from hospital. Use of social media, to raise carer awareness, particularly around Young Carers.

- Increase in identified carers on GP registers, council systems, and carers recorded as accessing commissioned services.
- An increase in the number of carers registered for a carer's passport.
- Carers will be signposted to the various avenues of support available at the earliest opportunity

• We will hear from carers that are involved with our strategic work, through local involvement networks and coproduction forums, that carers are being identified and signposted to appropriate information, advice and support

2. Carers are valued and involved - Caring today and in the future

What the engagement told us What will we carry forward What are our new setions			
What the engagement told us	What will we carry forward	What are our new actions	
Carers told us they would like simple acknowledgement of the role they play in supporting the person they care for. Carers still do not feel valued, they report feeling forgotten about during the pandemic and isolated. Those carers that are identified, report not being recognised as experts by experience in the health and wellbeing of the cared for. Carers reported lack of feeling valued, and comment this is often linked to not being recognised as a carer.	Further staff training – to ensure carers are recognised as experts by experience. Move towards a more co-productive approach to the planning and delivery of services. Ongoing work with hospital teams regarding discharge.	Create an agreed approach for communicating effectively with carers across Leicester Leicestershire and Rutland through the work of the Integrated Care system. The Carers Delivery Group will seek to influence and improve the information provided to carers around the differing care pathways across the system. Development of 'You Said We Did' approach – showing that carer voice influences and shapes the design and delivery of our services across the Integrated Care System Utilise an 'integration index' to be co-produced to measure the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care. Ensure that adult services are aware of and include young carers that may be involved in supporting the person receiving care.	

- Increased satisfaction level from carers within the next national carers survey
- Positive outcomes feedback from commissioned services
- We will hear from carers that are involved with our strategic work, through local involvement networks and coproduction forums that carers are recognised as experts by professionals involved in the care of their family member

What the engagement told us	What will we carry forward	What are our new actions
Knowing where to look for required information was noted as a barrier for carers. Carers told us that when they were identified as the main contact for the person they care for they were kept informed in some instances. Carers like to use their GP for information and support. Lack of recognition was cited as a barrier to being kept informed; carers feel they aren't offered the information as the person dealing with them doesn't view them as a carer.	Further awareness raising sessions planned for key staff to ensure all teams have access to knowledgeable staff member for support around working with carers which includes parent carers. Consider best communication pathways for sharing information with carers using learning from theCOVID-19 pandemic.	Ensuring carers can access the information they need, in the formats they require. This includes making sure information is available to those who may not be able to access information during usual office working hours Refresh of internet pages to ensure information clear, pages are easy to navigate and language used isn't "too corporate" which includes information for Young Carers. Including information on advocacy and getting carers voices heard. Development of relationships with schools and colleges to improve young carer awareness. Share learning from the trial of the Mobilise service in Leicester

- Increase in the proportion of carers who say they find it easy to find information about services
- Increase in carers identified
- Increase in numbers of carers accessing carer support

What the engagement told us	What will we carry forward	What are our new actions
Carers told us they would like to see the use of volunteers to support carers. Carers told us that by raising awareness of caring in communities, community venues and local businesses, they may become more accommodating. Some carers told us that they are isolated and not easily able to access services due to the availability of public transport. This is particularly relevant in rural areas	into account in future commissioning exercises, including consideration of updated geographic and demographic data from the updated census 2021. Continue to work with communities to support carers through awareness raising within existing community	We will ensure that the priorities within the Carers' Strategy are aligned with The Integrated Care Board's People and Communities Strategy 2022/2023 Continued promotion and growth of the Carers Passport scheme to include how this could be used in hospitals. Specifically targeting community schemes and groups within neighbourhoods. Development of relationships with schools and colleges to improve young carers awareness. Support carers to be able to access a broad range of services within their local communities, including voluntary/community led organisations, helping to support their wellbeing and alleviate social isolation.

- Carers report greater satisfaction in the accessibility of services
- Increase in the proportion of carers who say they find it easy to find information
- We will hear from carers that are involved with our strategic work, through local involvement networks and coproduction forums that the role of a carer is being noticed more within their community.

- Increase in number of carers accessing CareFree breaks.
- Increased satisfaction level from carers within the next national carers survey.
- Increase in the numbers of carers receiving information and advice regarding finance and benefits.
- Increase in number of young carers receiving transition assessments.
- The carer voice will be heard and listened to when local authorities are reviewing their respite provision.

What the engagement told us	What will we carry forward	What are our new actions
Local carers didn't identify with the previous title of priority 6 - Carers and the impact of Technology Products and the living space. However, what did come through was that carers have been reliant on technology or gadgets during the pandemic. There was acknowledgement that housing needs still exist, where properties aren't always suitable particularly for carers supporting someone who has severe needs.	We will continue to work with professionals from housing, equipment and adaptations to improve the carers' pathway and embed carer awareness.	Ensure carers are informed of technology solutions that can support them in their caring role. Work with carers so that they are reassured and confident about using technology and / or gadgets. Introduce mechanisms to better support patients, carers and volunteers to enhance 'supported self management' particularly of long-term health conditions.

- Increase in the proportion of carers who say they find it easy to find information
- Through our local involvement networks and coproduction forums, information will be shared with carers about various initiatives in relation to technology and we will hear feedback about how this has impacted on carers

7. Carers can access the right support at the right time - Services and Systems that work for carers			
What the engagement told us	What will we carry forward	What are our new actions	
Carers tell us they want to receive support that recognises their individual circumstances, that includes support to navigate through the health and social care system.		Forging robust links with the Mental Health programme of work across the integrated care system to ensure carers' needs are recognised.	
Carers want to be able to help themselves too and are looking for access to carer courses, to support them in their caring role.	Ongoing use of Carers Delivery Group (CDG) to ensure that all organisations work together to improve and join up support for carers wherever possible. People will be signposted to sources of support post-caring.	Ongoing use of Carers Delivery Group (CDG) to ensure that all the information provided to carers around differing care pathways across the system	The Carers Delivery Group will seek to influence the information provided to carers around the differing care pathways across the system. Targeted work to raise the profile of the Carers
Carers want support with health and wellbeing particularly mental health support for carers, as their caring role can have a negative impact on them at		Passports within hospital and GP services. To ensure that carers are supported to plan for emergencies.	
times. This can often be crucial when caring for somebody with a mental health condition, or for a great deal of time.		Work alongside LOROS and the Carers Matters Stakeholder group to understand what matters to carers supporting a loved one at the end of life.	
Carers require support with hospital discharge, starting right at the point of admission ensuring they are kept informed and involved.		Roll out of Young Carers passport across Leicester, Leicestershire, and Rutland.	

- Improvements in carer reported quality of life and satisfaction with social services through the bi-annual carer survey undertaken nationally.
- The numbers of carers receiving information and support at the right time will increase, and this will be reported through commissioned carer support services and other services supporting carers

What the engagement told us A number of Leicestershire young carers wanted to remove priority 8 and have actions for supporting young carers embedded within the actions for the other priorities. Young carers identified the need to be 'young people' and want time for themselves. Young carers want to be able to find the information they need. What will we carry forward What are our new actions Develop young carer support that acknowledges young carers often miss out on childhood and other key activities as well as providing appropriate mental health support where required. Embed the whole family approach. Working with educational establishments to continue to raise	8. Supporting Young Carers			
carers wanted to remove priority 8 and have actions for supporting young carers embedded within the actions for the other priorities. Young carers identified the need to be 'young people' and want time for themselves. Young carers want to be able to find the information they need. Develop young carer support that acknowledges young carers often miss out on childhood and other key activities as well as providing appropriate mental health support where required. Work with young carers to improve the way that the health system including GPs supports young carers	What the engagement told us	What will we carry forward	What are our new actions	
Young carers need support to identify as young carers, which is mindful of the needs of the whole family, particularly within schools, and colleges. Young carers say they often miss education due to their caring responsibilities which can impact their life choices. Local authorities will work with young carers to ensure that their aspirations of going to college, university, leaving home, are considered as part of their work with young carer services. Improve young carer support for those who are under 11 years of age	carers wanted to remove priority 8 and have actions for supporting young carers embedded within the actions for the other priorities. Young carers identified the need to be 'young people' and want time for themselves. Young carers want to be able to find the information they need. Young carers need support to identify as young carers, which is mindful of the needs of the whole family, particularly within schools, and colleges. Young carers say they often miss education due to their caring responsibilities which can impact their	Working with educational establishments to continue to raise	acknowledges young carers often miss out on childhood and other key activities as well as providing appropriate mental health support where required. Work with young carers to improve the way that the health system including GPs supports young carers Local authorities will work with young carers to ensure that their aspirations of going to college, university, leaving home, are considered as part of their work with young carer services. Improve young carer support for those who are	

- Increased number of young carers known to services will be reported.
- Young carers report feeling listened to and respected.
- Organisations can evidence a more robust approach to working with young carers and their families.

 The impact of caring on young carers is taken into account in assessments and transition planning across social care.
- Young carers report improved outcomes at home, school or in employment.

11. Monitoring progress

The Leicester, Leicestershire & Rutland Carers Delivery Group has led on the development of this strategy and recognises the impact that positive carer support can have across all workstreams. The group will oversee delivery of the strategy's priorities, and report progress to the respective partner organisations' governance arrangements and Health and Wellbeing Boards.

The Leicester, Leicestershire & Rutland Carers Delivery Group has representation from voluntary sector organisations who support carers, and also from Healthwatch who are responsible for sharing the experiences of carers with the group so that the carer voice is at the heart of its work. The group will also that those organisations representing carers are provided with information about progress under this Strategy so that they are able to feed this back directly to carers.