

## All Age Carers Strategy for Norfolk and Waveney 2024-2029

<b>1. Foreword.....</b>	<b>2</b>
Carolyn Fowler, Director of Nursing and Quality, Norfolk Community Health and Care NHS Trust. Executive Sponsor for Carers in the Integrated Care System	
<b>2. Preface.....</b>	<b>3</b>
Sharon Brooks, Chief Officer, Carers Voice Norfolk and Waveney	
<b>3. Background: State of Caring.....</b>	<b>4</b>
Definition	
National picture	
Carers in Norfolk and Waveney	
<b>4. Methodology and Co-production.....</b>	<b>6</b>
<b>5. Aims, Focus Areas and Recommended Actions.....</b>	<b>6</b>
Co-produced 'As a Carer' statements	
Focus areas and recommended actions across the Norfolk and Waveney Integrated Care System	
<b>6. Monitoring and Review.....</b>	<b>11</b>
How the All Age Carers Strategy for Norfolk and Waveney will be delivered, monitored and reviewed	
<b>7. Conclusion and ask of Norfolk and Waveney Integrated Care System.....</b>	<b>12</b>
<b>8. Appendix.....</b>	<b>13</b>
Appendix 1: Norfolk and Waveney Integrated Care System strategies	
Appendix 2: Types of caring role	
Appendix 3: Example roles shared by Carers in Engagement report	
Appendix 4: Co-produced 'As a Carer' statements with accompanying 'what would this look like/ feel like' points	
Appendix 5: List of organisations engaged	
Appendix 6: Examples of achievements since co-produced Engagement Report	
<b>9. References.....</b>	<b>27</b>

## **1. Foreword:**

**Carolyn Fowler**

Director of Nursing and Quality, Norfolk Community Health and Care NHS Trust.  
Executive Sponsor for Carers in the Integrated Care System

It's with great pleasure that I write the foreword for the All Age Carers Strategy – a vital document that has been co-produced in partnership and collaboration with Carers of all ages, backgrounds, and experience.

We have listened to Carers experiences of different challenges, be it with their own health and wellbeing, their access to education, the impact of inequalities in our population, and how it can often be difficult to be heard. The co-produced carer statements within the strategy come from our carers and talk about what they need, and how we can best demonstrate that we value what they do.

We will strive to focus on what matters to Carers, recognising that without them we could not care for people in the community as we do. The strategy identifies the importance of the health and wellbeing of carers, only if we look after them can they look after those they care for. The strategy will be implemented systemwide with measurable outcomes to improve support and services for Carers of all ages across Norfolk and Waveney.

## **2. Preface:**

### **Sharon Brooks - Chief Officer, Carers Voice Norfolk and Waveney**

Carers Voice Norfolk and Waveney are privileged to have been able to work with Carers to coproduce the first All Age Carers Strategy for Norfolk and Waveney. The strategy includes Young Carers, Young Adult Carers, Adult Carers and Parent Carers whilst recognising their different support needs. Carers Voice is a well-established charity with a membership of over 2400, working to empower the voices of Carers in the design and delivery of services across Norfolk and Waveney. Carers and co-production are at the heart of the work of Carers Voice (see appendix 6 for examples of co-production).

There is an absolute need for an All Age Carers Strategy now. Carers need our support at all times but, with the aftermath of Covid, the increased cost of living and pressures on our health and care services, Carers are desperately in need of support now so that they can stay well and continue to look after the people they care for should they wish to do so.

Carers across Norfolk and Waveney have given much of their time and shared their lived experience to inform this piece of work. Carers have seen that Carers Voice Norfolk & Waveney commit to improving the health and wellbeing of Carers. We understand that support for Carers has to encompass getting the best and most appropriate care at the right time for those they care for as well as supporting the Carer directly. Carers are in the unique position of balancing not only the needs of the person they care for but often their own support needs too, enabling them to see how well or not systems support the person they look after and themselves as a Carer.

This strategy has had the continued support of the Norfolk and Waveney Integrated Care Partnership (ICP) and its members who have committed to work with Carers on the focus areas and recommended actions to improve support for Carers so that they and the people they care for live their best possible lives. This Strategy aligns with the agreed priorities of the Norfolk and Waveney Integrated Care System strategies including the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024, the Ageing Well Strategic Framework and Health Inequalities Strategic Framework for Action 2024-2034 (See appendix 1 for further information).

We believe that through this work, change can happen systemwide and we are committed to continue to work and coproduce with Carers to develop and achieve the relevant actions through the Monitoring Group and associated activities.

Special thanks are due to all the Carers who have supported the development of the Strategy and particularly our Carer Ambassadors.

### 3. Background: State of Caring

#### Definition:

A Carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. (NHS England) When we refer to Carers in this document, this is inclusive of both adult and Young Carers.

**Types of caring roles:** Example caring roles can be viewed at appendix 2 and 3.

- **Adult Carers**
- **Parent Carers**
- **Young Carers**
- **Young Adult Carers**
- **Sandwich Carers** (Those with caring responsibilities for different generations, for example both children and parents)
- **Mutual Carers**
- **Carers of victims of crime and trauma**
- **Kinship Carers** (Kinship care means that children whose parents are unable to look after them on a short or long term basis are cared for by other relatives such as grandparents, uncles, aunts or siblings, or by other adults who have a connection to the child, such as neighbours or a close friend of the family)
- **Past Carers**
- **Distance Carers** (People caring for someone in Norfolk and Waveney who live outside of the area)
- **Hidden Carers** (People who look after someone but do not recognise themselves as being Carers)

#### National Picture:

There are 5.8 million Carers in the UK according to the most recent Census 2021, with 120,000 being Young Carers under the age of 18. This equates to around 9% of the population who are providing unpaid care. However, Carers UK research estimates that the number of people providing unpaid care could be as high as 10.6 million with a further 12,000 people becoming Carers every day. (Carers UK, 2022).

Carers in the UK are estimated to save the government £183.4 billion per year or over £500 million per day, which is equivalent to a second NHS (Petrillo, Zhang & Bennett, 2024). The cost of living crisis has caused increasing pressure on Carers finances with the latest Carers UK research indicating that 28% of Carers have cut back on essentials such as food or heating, 61% are worried about living costs and

managing in the future, with 60% having cut back on seeing family and friends. Over half of Carers said that their financial situation is negatively impacting their mental health (Carers UK, 2024).

One in seven people in the workplace are also unpaid Carers. (Carers UK, 2019). Within the NHS, this increases to one in three employees also providing unpaid care. (NHS Staff Survey, 2022).

50,000 children and young people spend at least 50 hours a week providing care. Carers Trust estimate that there are two Young Carers in every classroom in the UK. (Carers Trust, 2024)

Without the continued support of Carers, the health and social care services, which already faces significant demand challenges, would face further formidable challenges. Supporting Carers enables hundreds of thousands of people to be cared for in their own homes with a reduced pressure on the NHS. Providing timely support to people and their Carers helps prevent crisis and reduces the burden on the existing system.

Following the Health and Care Act of 2022, the Integrated Care Board for Norfolk and Waveney has a duty:

- To involve Carers in the planning and commissioning of services.
- To promote the involvement of Carers in decisions which relate to the prevention or diagnosis of illness or the care or treatment of the person they care for.
- To involve Carers in plans relating to discharge from hospital as soon as feasible if the person they care for is likely to require care and support.

### **Carers in Norfolk and Waveney:**

According to the 2021 census, there are approximately 95,000 Carers in the Norfolk and Waveney Integrated Care System with a fifth of these being Young Carers and Young Adult Carers. Many of these Carers are providing over 50 hours of care a week and care for more than one person.

Findings from the Carers Voice Co-produced Engagement with All Age Carers in Norfolk and Waveney Report 2022:

- Almost half of respondents (47.5%) provide more than 50 hours of care per week, and some of this will result from the number of respondents caring for more than 1 person (25.6%).
- Nearly 50% of Carers taking part in this survey had not received a Carer's Assessment. A further 20% were unsure if they had received an assessment, meaning that the number of respondents without an assessment could be as high as 70%.
- Carers who said there had been negative change to the following aspects of their lives where applicable:
  - Time for themselves: 76.28%
  - Mental health: 72.83%

- Day to day life: 71.69%
- Physical health: 56.84%
- Relationships: 57.79%
- Financial circumstances: 54.62%
- Employment: 53.44%
- Education: 32.48% (including separate Young Carers Engagement Survey)

## 4. Methodology and Co-production

In September 2022, having co-produced the Carers Engagement Report ([go to www.carersvoice.org to read this report in detail](http://www.carersvoice.org)), Carers Voice continued to develop and co-produce the All Age Carers Strategy on behalf of the Norfolk and Waveney Integrated Care Partnership. Building on the evidence base provided by extensive research with Carers, Carers Voice has worked systemwide with partners within Norfolk and Waveney. Throughout this period, the research has been supported by Norfolk County Council and the Norfolk & Waveney Integrated Care Board. Ongoing engagement has been facilitated through various methods to ensure broad participation including:

- Sense check survey
- All Age Carers Strategy Working Group
- Carers Involvement Meetings
- Carers Voice Norfolk and Waveney Partnership Meeting
- Carers Groups and public events
- Engagement with health, social care and Voluntary Community Social Enterprise (VCSE) partners (see appendix 5 for list of partners engaged)

## 5. Aims, Focus Areas and Recommended Actions

### Co-produced 'As a Carer' Statements:

The 'As a Carer' statements have been co-produced with Carers and are the overarching aims of the Strategy. They are accompanied with 'what would this look like/feel like' points which can be viewed in Appendix 4. The following statements formed the basis for the key focus areas and recommended actions for the first stage of delivery:

1. **As a Carer**, I have rights that will be upheld.
2. **As a Carer**, I am identified, recognised, valued and respected. I am an equal partner in the care of the person I look after which includes clear communication with me.
3. **As a Carer**, I am made aware of, and have access to, good quality information and services including a single and reliable point of contact.
4. **As a Carer**, I have access to good and appropriate support for my mental health, physical health and wellbeing.
5. **As a Carer**, I am an equal partner in the creation, development, monitoring and evaluation of services where my experience is recognised and valued. This will enable Carers, and the people we care for, to receive the services we

need and want. This is vital to support our health (including mental health) and wellbeing.

6. **As a Carer**, I can access education, employment and training.
7. **As a Carer**, I am able to have time for myself/ away from my caring role including access to peer support and community groups.
8. **As a Carer**, I know the person I care for will be safe and have access to a good quality of life if I am no longer able to care on a temporary or permanent basis.

### **Focus areas and recommended actions across the Norfolk and Waveney Integrated Care System:**

We have worked with Carers and practitioners across health and social care to coproduce the focus areas for the first stage of the strategy along with the recommended actions. These are broken down into seven Focus Areas detailed below:

#### **1. To identify and raise awareness of all ages of Carers, their rights and their value (including hidden Carers).**

#### **Recommended actions:**

- Recognise and promote the Carers Identity Passport.
- Organisations, including all educational settings, to have or be working towards local and national Carers accreditation.
- Carer Awareness Training (including information on Carers Rights) to be embedded in staff induction and regular training in all organisations including educational settings.
- Awareness of Carers Rights within mental health services.
- Participate in annual Carers Conference.
- Recognise national Carers weeks/days including Carers Week, Carers Rights Day and Young Carers Action Day.
- Identify and build support for Carers in community settings.
- Promote Carers Leave legislation and the right to discuss flexible working options.
- Work with Carers UK- [Employers for Carers](#).
- Support the employment of Carers in the recruitment and selection process, recognising Carers transferrable skills and experience.
- Have in place or be working towards a Carers Policy, which details Carers Rights and support available within the organisation.
- Integrated Care System Carers Page to include information on Carers Rights
- Carers Rights to be included in the All Age Carers Handbook.
- Promote a whole family approach to identification and support. Awareness of supporting parents with disabilities and identification of Young Carers not in school.

## **2. To improve access to good quality information and services including a single point of contact.**

### **Recommended actions:**

- Resources in different formats that are accessible to everyone (large print, easy read, screen reader accessible, translated).
- Ensure access to information and resources are available for those who do not have digital access.
- All communication to be in language that is familiar, precise and appropriate i.e. no use of acronyms.
- Identify a single, named and ongoing point of contact for Carers. For example, a Carers Lead identified within each educational setting.
- Emergency planning to be available to Carers of all ages including Young Carers and Parent Carers.
- Promote Norfolk County Council Carer Safeguarding toolkit. Inclusion of safeguarding information in the All Age Carers Handbook.
- Promote the 'Making Every Contact Counts' approach across statutory and Voluntary Community and Social Enterprise (VCSE) services, recognising that caring roles change.
- Promote the NHS 'Think Carer' principle across statutory and Voluntary Community and Social Enterprise (VCSE) services.
- Agree to contribute to the All Age Carers Handbook as appropriate.
- Promote Carers Assessments and the commissioned support services for Carers of all ages
- Improved information for Carers of self funders.

## **3. To recognise and involve Carers as equal partners in the care of those they look after.**

### **Recommended actions:**

- Ensure Advocacy Services include support for Carers.  
Develop a guide to involve Carers of all ages, recognising the additional complexities of identifying and including Young Carers.
- Ensure record of support Carers provide is captured- *long term support planning record*.
- To give realistic and clear information so Carers can make informed decisions.



**4. To co-produce services with Carers wherever possible, recognising their expertise and ability to influence and shape services that they need and want to support their health and wellbeing.**

**Recommended actions:**

- Agree to a standardised protocol for co-production ensuring Carers of all ages have an equal voice.
- Carers Lead identified within organisations, including all educational settings, who champions co-production with Carers and has capacity to drive appropriate change.
- Staff completing co-production training i.e. 'Making it Real training'.
- Involve Carers in service creation, development, monitoring and evaluation, recognising the impact on Carers when the support for the person they care for does not meet their needs.
- Integrated Care Board to safeguard Executive Sponsor for Carers position within the Integrated Care System (Currently Director of Nursing and Quality, Norfolk Community Health and Care NHS Trust).

**5. To recognise the importance of peer support and access to services which enable Carers to have a break from their caring role.**

**Recommended actions:**

- Clarity on eligibility from Social Services and commissioned services around breaks and respite offer for Carers for all ages.
- Recognise the importance of Carers Groups and maintaining an updated record.
- Support available digitally for Carers who cannot access support in the community due to availability of transport, alternative care or shielding.
- Recognise the rurality of Norfolk and Waveney and the need for viable options of transport when commissioning services.
- Support available to groups to help them continue.

## **6. To have a framework and knowledge of commissioned services for all age Carers.**

### **Recommended actions:**

- Identify interventions available and how these are accessed through the commissioned services.
- Commissioning organisations in the Integrated Care System to ensure Carers are involved in the commissioning process and ongoing when services have been commissioned.
- All services being commissioned for Carers to be presented to All Age Carers Strategy Monitoring Group to allow for continuity of service join up and avoiding duplication.
- The local authorities and Integrated Care Board commit to adopting "No Wrong Doors for Young Carers". [Go to \*\*carers.org\*\* to view the \*\*No Wrong Doors for Young Carers Memorandum of Understanding\*\*.](#)
- Research bodies to work with Carers at an early stage to design projects that are meaningful to Carers and the people they care for.

## **7. To develop a Carers pathway.**

### **Recommended actions:**

- Develop and increase identification of clear pathways to support Carers of different ages and stages of caring.
- Pathway of service commissioning.
- Promote transition needs for Young Carers moving schools and moving into adulthood.
- Promote positive transitions for Parent Carers between services.
- Promote commissioned services in Norfolk and Waveney as a one stop shop for Carers of all ages.
- Explore commissioned support for Kinship Carers.
- Encourage Carers to have a Carers Assessment to inform them of the support that they are entitled to.
- Encourage Care Act assessments and reviews to enable a discussion and recording of a person's needs and the provision available when a Carer is no longer able to care.

- Develop and promote a systemwide process to capture the support a Carer provides and the support needed if they are not able to care on a temporary or permanent basis - long term care planning.

## 6. Monitoring and review

### **How the All Age Carers Strategy for Norfolk and Waveney will be delivered, monitored and reviewed:**

It is important that the strategy will be a living document and is adaptable. Three main indicators will be used to measure the outcomes of the strategy. These will be linked to what extent the strategy has raised awareness, improved services and given rise to new ideas and projects. The indicators will be framed around the difference to Carers, services, funders and commissioners.

A Monitoring Group will be set up with Carers (representation from Adult Carers, Parent Carers and Young Carers) and representatives from services, organisations across health and social care and the VCSE organisations, funders and commissioners. The Monitoring Group will have overall accountability and responsibility for the action plan. The ongoing action plan will also be developed with reference to the NICE supporting adult Carers guidelines. The Monitoring Group will make sure the actions are accountable and will review the outcomes of the Strategy. The Monitoring Group will meet annually and separate subgroups will be set up where necessary. An annual conference to be held to share updates and successes.

The Monitoring Group will coproduce a monitoring form and annual survey. The Monitoring Group will collectively agree on data to be collected with a discussion on what success would look like for service providers. Some of the suggested metrics are:

- Number of Carers Identity Passports issued
- Number of Carers who have had a Carers Assessment
- Carers Handbook production
- Data from training providers

There will be ongoing intelligence gained through engagement with all age Carers across Norfolk and Waveney i.e. Carer Involvement and Carer Partnership Meetings, Carers Forums across health and social care, Carers Groups, Carers Ambassadors, Parent Carer Forums, Healthwatch Norfolk, Healthwatch Suffolk, Norfolk Learning Disability Partnership Board, Norfolk Autism Partnership Board and Norfolk Young Carers Forum.

Some examples of what has been achieved so far include the co-production of the Carers Identity Passport (see appendix 6) for all age Carers in Norfolk and Waveney as well as the systemwide discharge project which has culminated in a co-produced booklet for Carers.

## **7. Conclusion and ask of the Norfolk and Waveney Integrated Care System**

Helen Walker, Chief Executive, Carers UK said, “*Without the high level of care that unpaid Carers provide, our health and care systems would quite simply collapse.*” (Petrillo and Bennett, 2023). It is essential that support for Carers of all ages is addressed effectively and prioritised. They are the hidden backbone of society often referring to themselves as ‘propping up’ the health and social care system. By ensuring effective support for Carers across Norfolk and Waveney, we will not only empower Carers to live their best possible lives but also enhance the quality of care for the people they care for. We have the opportunity to work together to create a sustainable future where Carers are respected and supported as invaluable contributors to society. The All Age Carers Strategy aligns with three key strategies across the Norfolk and Waveney Integrated Care System (See appendix 1).

### **On 4th December 2024 the Integrated Care Partnership for Norfolk and Waveney agreed to:**

- Endorse and promote the All Age Carers Strategy for Norfolk and Waveney 2024 - 2029
- Commit to supporting the All Age Carers Strategy for Norfolk and Waveney by sending representatives to be part of the Monitoring Group as appropriate
- Ensure all partners commit to developing action plans for supporting based on the Focus Areas and Recommended Actions within the Strategy document

### **The Integrated Care System agreed to work in the following ways:**

- Promote and include the work of the All Age Carers Strategy systemwide through the Norfolk and Waveney Integrated Care System Strategies and Frameworks
- Review the commitment to Carers through the Strategy at regular intervals
- Commit to co-production within their organisations wherever possible
- Ensure Carers are treated as equal partners in the design, development and delivery of services that support Carers and those they care for

## 8. Appendix

### Appendix 1: Norfolk and Waveney Integrated Care System Strategies

The All Age Carers Strategy aligns with the agreed priorities of the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024 of Driving integration; Prioritising Prevention; Addressing Inequalities and Enabling Resilient Communities to enable systemwide support for the people of Norfolk and Waveney to live longer, healthier and happier lives. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Integrated Care Strategy and Norfolk Joint Health and Wellbeing Strategy 2024.](https://improvinglivesnw.org.uk)

The work of the All Age Carers Strategy is key to the success of the ninth priority of supporting the needs of families and Carers in the Ageing Well Strategic Framework of the Norfolk and Waveney Integrated Care System which underpins the nine strategic goals of the framework. [Go to improvinglivesnw.org.uk to read the Ageing Well Strategic Framework in detail.](https://improvinglivesnw.org.uk)

Supporting Carers and the people they care for enables greater understanding of the experiences of living with health inequalities and what factors influence outcomes. This strategy supports the work of the Norfolk and Waveney Health Inequalities Strategic Framework for Action 2024 – 2034, in particular Young Carers who are identified as one of the Core20plus groups. [Go to improvinglivesnw.org.uk to read the Norfolk and Waveney Health Inequalities Strategic Framework](https://improvinglivesnw.org.uk)

## Appendix 2: Types of caring roles:

- **Working Carers-** I support my Mum who has dementia. I support with all household tasks, shopping, collecting medication, arranging appointments etc. She lives on her own at the moment, but I am worried about the future as she is forgetting more and more. I also work full time so having to juggle everything is really hard. I feel guilty when I have to leave but I don't have any time for myself and I am exhausted. We have talked about getting care staff in but Mum doesn't want 'strangers' in the house. So, for now, it's just me.
- **Mutual Carers-** I have been looking after my wife for over 20 years who has bipolar but only realised I was a Carer when someone said to me I was. When she experiencing a low mood, I have to encourage her to get up from bed, make sure she is eating enough and encourage her to go outside as I know this helps her feel better. My wife is now supporting me as my physical health has deteriorated. We look after each other, this is part of our marriage vows.
- **Distance Carer-** I live in Coventry which is over 3 hours away from my sister. I provide a lot of emotional support and reassurance over the phone and visit as much as possible. I coordinate all care and support over the phone. She is fortunate to have a good friend who lives nearby that takes her to appointments
- **Carers of victims of crime and trauma-** I am a Carer for my child who is a victim of online grooming and sexual assault. I provide ongoing emotional support and help with everyday life. It is really difficult for me to talk to people about this. We are a group of Carers that are not always recognised
- **Young Adult Carers-** I help my parents look after my younger sister. I have recently learnt how to drive, and I take my sibling on drives around the block to help calm her. I am planning on going to university next year but am worried about how they will cope.
- **Parent Carer-** I look after my son who is autistic. I provide emotional support, admin support with all bills and documents, help booking and attending appointments, prompting to take medication etc. I am so worried about how he is going to cope when I am not here.
- **Adult Carer-** have found myself in a situation where I am caring for someone I have no emotional attachment to.
- **Young Carers-** I help my mummy and daddy look after my brother who is autistic. He doesn't like loud noises and can get really upset.
- **Changing caring role-** I have been looking after my wife for over 15 years but she has gradually needed more care and moved into a care home at the start of the year.
- **Sandwich Carers, Carers with responsibilities for different generations, for example both children and parents)-** I am looking after my child who has SEND and my dad who has dementia. My dad has paid carers coming in three times a day to support with personal care and making sure he has a meal. They often only have time to give him a microwave meal so I try and cook him a home cooked meal once a week. Me and my siblings go round when we can to sit and chat with him, so he's not lonely. This year my child is 18 and I am worried about moving from Children to Adult Services.
- **Past Carers -** I was looking after my partner for over 10 years. Once a Carer, always a Carer.

- **Hidden Carers (People who do not realise they have a caring role)-** I am just a:
  - Parent
  - Spouse
  - Partner
  - Child
  - Sibling
  - Relative
  - Friend
  - Neighbour

People do not always want the label. Cultural expectations differ.

- **Kinship Carers-** I am an adult looking after my younger sibling who is a child. It is difficult for me to access support as I don't fit in a box.
- **Parent Carer -** I am a Carer of a child with SEND. I also have a disability myself.

### **Appendix 3: Example roles shared by Carers in the Engagement Report**

- **Meals-** preparing, cooking, nutrition, cutting food up, feeding, reminding to eat, buying food
- **Help with incontinence-** washing linen, changing pads, help to go to the toilet, prompt to go to the toilet, supporting/checking during the night
- **Appointments-** liaising with the doctors and hospital, being the point of contact, travelling to appointments, accompanying to appointments, emotional support to go appointments, being contact due to poor hearing
- **Shopping-** food, household supplies, monitoring and topping up supplies within the house
- **Personal care-** washing, bathing, reminders to shower, shaving, changing, choosing appropriate clothes, help with toileting
- **Moving and practical help-** transferring from bed to chair, help with walking, pushing wheelchair, moving and handling, lifting items including drinks, using hoist
- **Healthcare-** catheter maintenance, massaging painful joints, delivering physiotherapy, monitoring and treatment that local services are unable to provide, help with hydration and nutrition, checking blood pressure and blood sugar levels
- **Everyday tasks-** shopping, cleaning, tidying, reminders, dealing with mail, gardening, assistance with daily needs, dog walking, prompts, lifting, sorting heating, making sure house is an appropriate temperature, switching off lights
- **Monitoring-** checking in overnight, checking in daily, medication, health, how treatment is working
- **Safety-** support with danger awareness, supervising, safety in kitchen with kettle and hob, safety around the home including trip hazards, online safety, checking doors are locked, road safety
- **Emotional support-** listening, phone calls, reassurance, check ins, support to take part in activities, support with panic attacks and nightmares, calming, encouraging, distracting, support with decision making, support with time keeping, constantly answering questions
- **Social support-** keeping company, combatting loneliness, arranging visitors and social activities, companionship, connecting with others
- **Medication-** collecting medication, ensuring medication is taken, monitoring supplies of medication

- **Falls-** supervise safety to prevent falls, supporting if regular falls occur
- **Activities-** encourage activities to stimulate brain function, mental stimulation, transport to activities, support to attend activities
- **Communication-** being the primary contact, explaining what is going on due to impaired hearing, advocating, help with finding words, changing hearing aids, help understanding instructions, interpretation including signing, support as very poor eyesight
- **Organisation-** arranging care, coordinating services, oversight of support, diarise appointments
- **Finance-** overseeing utilities, paying bills, budgeting support, all paperwork, poor eyesight so all personal admin
- **Support with sensory needs**
- **Teaching-** home education, how to manage emotions, support to manage bills and money, teaching how to communicate with new technology
- **Providing childcare-** looking after children, school pick ups
- **Support with technology-** using technology including iPad, phone, tv

#### **Appendix 4: Co-produced 'As a Carer' statements with accompanying 'what would this look like/ feel like' points**

##### **1. As a Carer, I have rights that will be upheld.**

##### **What would this look/feel like:**

- All Age Carers are provided with access to information and training about their rights and support with getting these.
- Training on Carers Rights (for all age Carers) and support available is included in staff induction and regular training.

##### **Information about Carers Rights:**

##### **Care Act 2014 and Children and Families Act 2014**

##### **Adults caring for other adults**

Under the Care Act, you are entitled to a Carer's Assessment where you appear to have needs for support. The person you care for is entitled to a 'needs assessment' if they appear to have needs for care and support.

##### **Young Carers and Parent Carers**

The Children and Families Act 2014 gives Young Carers and Parent Carers in England a right to an assessment of their own needs.

Young Carers are equally entitled to have a Carers Assessment. There are different types of assessments for Young Carers depending on how old they are.

1. Young Carer's assessment for Carers under 18.
2. Transition assessment for Young Carers before they are 18 (Care Act 2014).



Parent Carers are also entitled to have a Parent Carer Needs Assessment.

### **Equality Act 2010**

The Equality Act 2010 was introduced to stop discrimination and promote equality. The Act could help you if you care for someone who is elderly or disabled. It could protect you against direct discrimination or harassment because of your caring responsibilities. This is because you are counted as being 'associated' with someone who is protected by the law because of their age or disability. If you're treated less favourably than someone else because you're caring for an elderly or disabled person, it is called 'Discrimination by Association'.

### **The Health and Care Act 2022**

This legislation reinforces Carers' rights when it comes to hospital discharge. If someone is likely to need ongoing care and support after they leave hospital, NHS trusts and foundation trusts have a duty, where appropriate, to involve patients and Carers (including Young Carers) at the earliest opportunity in decisions and plans around their ongoing care needs.

### **Flexible Working Act 2023**

If you are juggling work with your caring responsibilities, you have the right to request flexible working. The introduction of the new Employment Relations (Flexible Working) Act means that anyone, including unpaid carers, can ask their employer for changes to their working hours, times of work, or place of work, from day one. They will also be able to change their flexible working arrangement more than once a year.

### **Carers Leave Act 2023**

The Carer's Leave Act came into effect on the 6 April 2024.

- The Carer's Leave Act covers employees in England, Wales and Scotland.
- Employees are entitled to one week's unpaid leave per year if providing or arranging care for someone with a long-term care need.
- This leave can be taken flexibly (in half or full days) for planned and foreseen caring commitments.
- It is available from the first day of employment.
- It provides the same employment protections to employees as other forms of family-related leave, including protection from dismissal.

### **The right to ask your GP practice to identify you as Carer**

People providing unpaid care can ask their GP practice to identify them as a Carer on their patient record. The benefit of this is that they may then fall into a priority group for vaccines or other public health campaigns.

**2. As a Carer, I am identified, recognised, valued and respected. I am an equal partner in the care of the person I look after which includes clear communication with me.**

### **What would this look/feel like:**

- Carers are identified and recognised (including Young Carers, Parent Carers and Carers of victims of crime and trauma) as a key partner across health and social care.
- Professional practice and processes are developed across the Norfolk & Waveney Integrated Care System for raising awareness of Carers of all ages (and the wider family) and the All Age Carers Strategy for Norfolk and Waveney.
- A whole family approach to identification and support will be promoted across health and social care.
- The knowledge and experience of Carers of all ages is valued and they are supported and included in plans of those they care for at the earliest possible stage.
- Language is used that is recognised (are you looking after someone?). Language needs to be inclusive and understood by Carers of all ages and those who do not recognise themselves as a Carer.
- Increased communication and data between health and care services so Carers only have to tell their story once.
- Awareness and support for Carers of all ages in community settings.
- Carers are an equal part of the team in the **triangle of care** (partnership between practitioners, the person being cared for, and their Carers).

### **3. As a Carer, I am aware of and have access to good quality services including a single and consistent point of contact.**

#### **What would this look/feel like:**

- Carers of all ages can easily access information (available in different formats and languages), advice, guidance and good quality support when and how they need it, early in their caring role.
- Improved communication between services and departments with consistent messages.
- Carers of all ages have equal and appropriate access (no wrong door). There is a clear route to access support.
- Positive transitions for Young Carers and Parent Carers between services.
- The need for human contact is recognised.
- Improved navigation of services including identifying and maintaining a **single point of contact**.
- Information about pathways for specific conditions.
- Awareness of the need for more recognition of all age Carers amongst community and wider advice services i.e. employment support.

- GP surgeries, hospitals and educational settings recognised as often the first point of contact.
- Recognise how community infrastructure can support Carers of all ages.
- Self-funders have access to information and support in their caring role.

#### **4. As a Carer, I have access to good and appropriate support with my mental health, physical health and wellbeing**

##### **What would this look/feel like:**

- Access to support is available for all age Carers which is flexible and personalised.
- Recognise the impact caring can have on a person's mental health, physical health and wellbeing. If support is not appropriate and timely for the person being cared for, this may contribute to Carer breakdown and/or crisis and negatively affect their finances.
- Staff have a working knowledge about the support available to Carers and are able to signpost and refer. *Making every contact count*.
- Regular contact/ check ins with Carers to touch base and check they are receiving the support they need.
- Mental health is everyone's responsibility.
- Always check that Carers are willing and able to continue in their caring role
- Support for all age Carers to access flexible appointments.
- All age Carers have access to a break from their caring role to have time to focus on their own health and wellbeing.
- Identify the importance of peer support, companionship, listening ear and time for themselves. Support all age Carers to improve connections to reduce social isolation.
- Coordinated support for Carers of all ages and people they care for. Services need to be person centred to enable people to live their best lives possible.
- Packages of care and support are appropriate at the outset and flexible to reflect change. Safeguards in place to avoid delays and inappropriate levels of support.
- Consistent support including when a caring role changes or ends.
- Young Carers have the same opportunity to achieve their aspirations (recognising the Norfolk County Council Flourish Ambition in Norfolk).

**5. As a Carer, I am an equal partner in the creation, development, monitoring and evaluation of services where my experience is recognised and valued. This will enable Carers and the people we care for to receive the services we need and want. This is vital to support our health (including mental health and wellbeing).**

**What would this look/feel like:**

- Carers of all ages are included in the design and delivery of services from the start and through to ongoing decision making.
- Carers of all ages receive the support they need to be involved in decisions for the person they care for and for themselves
- Organisations across the Norfolk and Waveney Integrated Care System work together and pool knowledge to share expertise. Consultations are not repeated.

**6. As a Carer, I can access education, employment and training.**

**What would this look/feel like:**

- Early identification of Carers of all ages in educational and workplace settings.
- Allow for flexible arrangements to be made to support Carers of all ages with education, employment and training. A Carers Lead/ Carers policy is identified within educational and workplace settings.
- Recognising and creating opportunities for employment, training and volunteering.
- Support for all age Carers and organisations to recognise Carers' transferable skills and experience.
- Carers of all ages have access to employment, financial and benefit advice and support.
- Training for Carers on their rights to enable and empower them to carry out their caring role.

**7. As a Carer, I am able to have time for myself/ away from my caring role including access to peer support and community groups.**

**What would this look/feel like:**

- Availability of and access to services so Carers of all ages can have a break and time to focus on their own health and wellbeing. This is flexible to meet the needs of the Carer and the people they care for.

- Carers of all ages can access peer support within the community.
- Support and encourage Carers to access a Carers Assessment and the people they care for to have a needs assessment.
- Awareness and links with support in the community.

**8. As a Carer, I know the person I care for will be safe and have access to a good quality of life if I am no longer able to care on a temporary or permanent basis.**

**What would this look/feel like:**

- A clear process is in place for long term care planning and this is linked systemwide to allow for multi-agency support.
- Planning is person centred.
- Recognition of complex needs and range/depth of support required in planning for the future.
- Recognising the continued role of all age Carers when the person they care for is in an alternative place of care.
- Early identification of requirements.
- Awareness of emergency planning.
- Emergency planning to be available to Carers of all ages including Young Carers and Parent Carers.
- Carers of all ages and people being cared for have access to an advocate.

**Appendix 5: Organisations engaged**

- Access Community Trust
- Active Norfolk
- Age UK Norfolk and Norwich
- Ageing well
- Anglia Ruskin University

- ARC East of England Carer Research Network
- ASD Helping Hands
- Bridges Outcomes Partnerships
- Bridges Plus
- Carers Charter
- Carers Matter Norfolk
- Carers UK
- Carers Voice Members (approx. 2400)
- Carers Voice social media
- Caring Together
- Chief Nurses Norfolk and Waveney
- Community Action Norfolk
- Deaf Connexions
- DIAL (Disability
- EACH
- East Coast Medical Healthcare
- East of England Ambulance Service
- East Suffolk Council
- Equal Lives
- Family Voice Norfolk
- Great Yarmouth and Gorleston Young Carers
- Headway Norfolk and Waveney
- Health and Wellbeing Partnership Chairs (Breckland, Broadland, Great Yarmouth, Kings Lynn and West Norfolk, North Norfolk, South Norfolk, Norwich and Waveney)
- Healthwatch Norfolk
- Healthwatch Suffolk
- Independence Matters
- James Paget University Hospitals NHS Foundation Trust
- Later Life Partnership Network
- Lowestoft Rising
- Making it Real
- Mancroft and Advice Project (MAP)
- Mind
- MND (Motor Neurone Disease) Association
- NCAN (Norfolk Community Advice Network)
- Norfolk & Waveney Dementia Support Service
- NHS Norfolk & Waveney Integrated Care Board (Ageing Well Programme Board, Dementia Working Group, Children and Young People - Quality in Care, Patient Experience, Care Homes and Housing, Health Inequalities)
- Norfolk and Norwich University Hospitals NHS Foundation Trust
- Norfolk and Suffolk Care Support
- Norfolk and Suffolk Foundation Trust
- Norfolk Autism Partnership Board

- Norfolk Community Health and Care NHS Trust
- Norfolk Community Law Service
- Norfolk County Council Adult Social Care/Children's Services
- Norfolk County Council Care Provider Network
- Norfolk County Council Development Workers networks
- Norfolk Hospices
- Norfolk Local Pharmaceutical Committee
- Norfolk Learning Disability Partnership Board
- Norfolk Older People's Strategic Partnership
- Norfolk Primary Care
- Norfolk Safeguarding Adults Board
- Norfolk Young Carers Forum
- Norfolk's All Age Autism Strategy 2024-2029
- North Norfolk Dementia Working Group and Ageing Well Programme Board
- Opening Doors
- Patient Experience Network Norfolk and Waveney
- Patient Experience, NHS England
- Place Board Chairs (Great Yarmouth and Waveney, North Norfolk, Norwich, South and West)
- Police and Crime Commissioner for Norfolk
- Police and Crime Commissioner Suffolk
- Priscilla Bacon Hospice
- Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust
- Restitute
- St Elizabeth Hospice
- Suffolk County Council
- Suffolk Family Carers
- Suffolk Parent Carer Forum
- Suffolk Safeguarding Partnership
- Tapping House
- University of East Anglia
- Voluntary Norfolk
- West Norfolk Deaf Association
- West Norfolk Carers
- Young Carers Matter Norfolk
- Young Carers Norfolk Steering Group

## **Appendix 6: Examples of achievements since co-produced Engagement Report**

### **Carers Identity Passport for Norfolk and Waveney**

The Carers Identity Passport has been co-produced with Carers and practitioners across the Norfolk & Waveney Integrated Care System to ensure Carers are identified and recognised within healthcare settings. It is for all age Carers, including

Young Carers and Parent Carers, in Norfolk & Waveney. It is available both physically as a card and a lanyard and digitally as an image Carers can save onto their phones.

The Carers Identity Passport is aimed to be a conversation starter to ensure Carers are recognised, valued and respected in their caring role and included in the care of the person they are looking after. It helps Carers to be linked into the existing support within the hospitals (flexible visiting, free parking etc) and wider support for Carers available from other organisations. The card has a QR code and link to the Norfolk and Waveney Integrated Care System website which has a page with information about support for Carers of all ages.



*Figure 1 Photo of the Carers Identity Passport card and lanyard and digital Carers Identity Passport*

The Carers Identity Passport is free for Carers to request. Carers can apply for a Carers Identity Passport by completing a short form available at: <https://www.carersvoice.org/carers-identitypassport/>. There is a number to call for support with completing the form, this is **07932095312**.

Carers tell us that this passport is key to their identification for support. It is a tangible sign that they are recognised, valued and respected. The digital version enables Carers to discreetly refer to them in a sensitive situation or they wear the lanyard and badge to be easily recognised – Young Carers tell us they wear them with pride in school.

*I wear the Carers Identity Passport wherever I go with the person I care for, it helps to show I am a Carer... it has been recognised without question, which makes me feel empowered as an unpaid Carer.*

As of 15<sup>th</sup> November 2024, 4240 Carers Identity Passports have been issued. [Go to www.carersvoice.org](https://www.carersvoice.org) to view a visual overview of the co-production of the Carers Identity Passport. [Go to www.carersvoice.org](https://www.carersvoice.org) to view a summary report which sets out what Carers told us during this project and what we did as a result.

### **Carers Discharge Project:**

A multi-agency discharge group was set up following feedback received from Carers about the discharge process. This work is being co-chaired by a Carers Voice Carers Ambassador, Graham Goodwin and the Executive Sponsor for Carers within the Norfolk and Waveney Integrated Care System (currently Director of Nursing and



Quality, Norfolk Community Health and Care NHS Trust). The sessions were held to provide a platform for Carers to articulate their experiences, address concerns, and explore factors that could improve the discharge experience for Carers. Providers shared their existing work to support Carers in the discharge process, highlighting both successful practices and areas needing improvement.

The work has culminated in the co-production of a booklet for Carers to use when the person they care for is admitted to hospital through to when they are discharged and beyond. The goal is to generate tangible improvements for Carers, enhancing their overall experience with discharge. The booklet will contain sections covering the following topics:

- Support for Carers
- Supporting the person you are caring for during their hospital stay
- Preparing for discharge
- Checklist

The Discharge Booklet will be piloted in the Queen Elizabeth Hospital in Kings Lynn and Norfolk Community Health and Care NHS Trust in West Norfolk (Swaffham Community Hospital)

## References:

Bennett, M.P., Matt (2023). *Value of unpaid care in England and Wales now exceeds that of NHS budget*. [online] The Centre for Care. Available at: <https://centreforcure.ac.uk/updates/2023/05/valuing-carers/>

Carers Trust (2024). *Carers Trust launches landmark Young Carers Covenant to transform the lives of over one million children*. [online] Carers Trust. Available at: <https://carers.org/news-and-media/news/post/361-carers-trust-launches-landmark-young-carers-covenant-to-transform-the-lives-of-over-one-million-children>

Carers Trust (2024). *'No Wrong Doors for Young Carers' - Working together to support young carers and their families. A template for a local memorandum of understanding for a whole-system approach to identifying and supporting young carers, young adult carers and their families*. [online] Carers Trust. Available at: [https://carers.org/downloads/no-wrong-doors-for-young-carers---mou-\(final-version\).pdf](https://carers.org/downloads/no-wrong-doors-for-young-carers---mou-(final-version).pdf).

Carers UK (2024) *The impact of caring on: finances State of Caring 2024*. [online] Carers UK. Available at: <https://www.carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf>

Carers UK (2022). *12,000 people in the UK become unpaid carers every day*. [online] Carers UK. Available at: <https://www.carersuk.org/press-releases/12-000-people-in-the-uk-become-unpaid-carers-every-day>

Carers UK (2022). *Key facts and figures*. [online] Carers UK. Available at: <https://www.carersuk.org/policy-and-research/key-facts-and-figures>

Carers UK (2022). *State of Caring 2022 report*. [online] Carers UK. Available at: <https://www.carersuk.org/reports/state-of-caring-2022-report>

Carers UK (2019). *Carers UK responds to 2022 NHS Staff Survey results* [online] Carers UK. Available at: <https://www.carersuk.org/press-releases/carers-uk-responds-to-2022-nhs-staff-survey-results/>

Carers UK (2019). *Juggling work and unpaid care. A growing issue*. [online] Carers UK. Available at: <https://www.carersuk.org/media/no2lwyl/juggling-work-and-unpaid-care-report-final-web.pdf>

Carers Voice. (2022). *Co-produced Engagement with All Age Carers in Norfolk and Waveney Summary of Approach and Main Findings*. [online] Carers Voice. Available at: <https://www.carersvoice.org/wp-content/uploads/2023/01/Final-Carers-Engagement-Report-NorfolkandWaveneyNovember-2022.pdf>

Norfolk Safeguarding Adults Board. (2021). *Carers and safeguarding | Norfolk Safeguarding Adults Board*. [online] Available at: <https://www.norfolksafeguardingadultsboard.info/protecting-adults/carers-and-safeguarding>

National Institute for Health and Care Excellence (2020). *Supporting adult carers NICE Guideline*. [online] NICE Available at: <https://www.nice.org.uk/guidance/NG150>.

NHS England (2014). *NHS commissioning» Principle 1 – Think carer, think family; make every contact count*. [online] NHS England. Available at: <https://www.england.nhs.uk/commissioning/comm-carers/principles/principle-1/>.

Norfolk County Council (2023). *Young Carers and Families in Norfolk Needs Assessment*.

Norfolk County Council (2021). *Flourishing in Norfolk: A Children and Young People Partnership Strategy*. [online] Norfolk County Council. Available at: <https://www.norfolk.gov.uk/article/39199/Flourishing-in-Norfolk-A-Children-and-Young-People-Partnership-Strategy>.

Petrillo, M. and Bennett, M.R. (2023) *Valuing Carers 2021: England and Wales*. London: Carers UK.

Petrillo, M., Zhang, J., and Bennett, M.R. (2024) *Valuing Carers 2021/2022: the value of unpaid care in the UK*. London: Carers UK. Available at: [Valuing Carers 2021/22: the value of unpaid care in the UK](#)

Public Health England (2016). *Making Every Contact Count (MECC): Consensus Statement*. [online] *NHS England*. Public Health England. Available at: <https://www.england.nhs.uk/wp-content/uploads/2016/04/making-every-contact-count.pdf>.