# Identifying and supporting unpaid carers in England to improve integrated system working

A resource for health and social care professionals

February 2025









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### **About this resource**

This resource has been developed by the Carers Partnership (Carers UK and Carers Trust) as part of the Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance, with the input of unpaid carers, professionals working in health and social care, virtual wards leaders, local carers' organisations and local authorities. We are grateful for their input, along with colleagues at NHS England and the Department of Health and Social Care.

Its purpose is to support health and care systems in England to improve the inclusion, support, and involvement of unpaid carers. It brings together statutory duties and best practice resources developed by the Carers Partnership (2022–2025), to help health and care professionals reduce the health inequalities carers face, better identify unpaid carers, and drive transformative change.

### Who is an unpaid carer?

An unpaid carer is anyone, including children and adults, who provides care or support to a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction.



### Why supporting unpaid carers matters

# Carers play a vital role in supporting the NHS and social care systems

- 4.7 million people provide unpaid care in England, with 1.4 million people caring for over 50 hours a week.<sup>1</sup>
- In England, unpaid carers outnumber the paid health and care workforce by 2:1.
- Carers' support in England is worth £152 billion a year – equivalent to spending on the NHS in England.<sup>2</sup>

Social determinants of health are the broad social and economic circumstances that influence a person's health and wellbeing outcomes.

# Caring is a social determinant of health

- In 2021, Public Health England identified caring as a social determinant of health.<sup>3</sup>
- ONS data shows that half (49%) of unpaid carers who provide substantial care report at least one adverse health effect due to providing care.<sup>4</sup>
- GP Patient Survey 2024, which was completed by over 2.5 million patients, found that 70% of carers who responded had a physical or mental health condition or illness expected to last more than 12 months, compared with 59% of non-carers.<sup>5</sup>
- Caring has a huge impact on people's mental health. 27% of carers who responded to Carers UK's State of Caring survey said their mental health is bad or very bad, and 82% said the impact of caring on their physical and mental health will be a challenge over the next year.

### Carers struggle to get the support they need

- 54% of unpaid carers providing 50+ hours of care per week and 29% of those providing 20-49 hours of care per week said that they don't get enough support as an unpaid carer.<sup>6</sup>
- Many carers face delays in obtaining both primary and secondary health care appointments, and 42% of carers say they need more support from the NHS or healthcare professionals.<sup>7</sup>
- Many carers are not currently getting the support they are entitled to under the Care Act 2014. 23% of carers say care services are not currently meeting their needs.<sup>8</sup>
- 88% of directors of adult social services recently reported an increased level of need among carers, identifying carer burnout as the leading factor contributing to carer breakdown.<sup>9</sup>

# Legal responsibilities towards unpaid carers across health and social care

There are several statutory duties (or legal responsibilities) to support unpaid carers that are placed on public health and social care bodies, like local authorities and Integrated Care Boards (ICBs).

Legislation is often supported by statutory policy guidance which also helps set out expectations to explain parts of the law. This has the equivalent of the force of law.

These legal responsibilities are outlined on pages 7 and 8, and we provide more detailed information in Annex 1.

As professionals who are likely to be in contact with carers, you play a key role in delivering these responsibilities. It is therefore essential to understand the legal duties in place to ensure carers receive the support they are entitled to under the law.



### **Carer-specific legislation**

## Health and Care Act 2022

The Health and Care Act 2022 contains four key provisions in relation to carers:

- **Section 10:** Places a duty on NHS England to consult carers and other representatives regarding commissioning or policy decisions which affect service provision and delivery.
- **Section 25:** Places a duty on Integrated Care Boards to promote the involvement of unpaid carers, where appropriate, in relation to decisions about prevention, diagnosis, treatment and care.
- **Section 25:** Places a duty on Integrated Care Boards to consult carers in commissioning or policy decisions affecting services.
- **Section 91:** Places a duty on NHS Trusts and Foundation Trusts to involve carers, where appropriate, in planning for hospital discharge as soon as is feasible.

#### Care Act 2014

The Care Act 2014 requires local councils to assess unpaid carers, provide support to meet their needs, and promote carer-wellbeing. Duties also include providing information, advice, and support to prevent carers from developing further support needs. Local councils also have a duty to involve unpaid carers in the design of services that affect them.

### Children and Families Act 2014

The Children and Families Act 2014 protects children, as well as offering specific protection to young carers and parent-carers of disabled children (including those with a long-term condition). It specifies that local authorities must meet their duties to identify, assess and support young carers, young adult carers and their families.

#### **Carer's Leave Act 2023**

The Carer's Leave Act 2023 makes provision for employees who balance work with unpaid caring responsibilities to take up to one week of unpaid carer's leave per year, if providing or arranging care for someone with a long-term care need. There are other workplace rights which support carers in employment, which are set out **here**.

### Other legislation in support of carers

#### Carers also have rights and protections through other pieces of legislation:

Equality Act 2010	The Equality Act 2010 protects unpaid carers against discrimination or harassment as they are
	considered to be associated with someone with a protected characteristic (disability).

Human Rights Act 1998
Under Article 8 of the Human Rights Act 1998, individuals, including carers, are granted the right to respect for private and family life, home and correspondence. Carers also have the right to freedom from inhuman and degrading treatment under Article 3.

### In practice, what does this mean for health and social care professionals?

- Proactively identifying and recognising carers
- Offering carers timely and relevant information
- > Connecting carers to local or relevant support services
- > Supporting carers to access a carer's assessment
- > Providing support following the outcomes of a carer's assessment
- > Involving carers in relevant decisions about health and social care services
- Involving carers in any strategic planning or delivery of services

The National Institute for Health and Care guideline, 'Supporting adult carers' (NG150), also includes information and guidance for health and social care practitioners on identifying and supporting adults over the age of 18 who provide care for people aged 16 or over with health and care needs. It includes carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

### Resources to help you support unpaid carers

This section provides information, resources and best practice examples to help health and care professionals to support unpaid carers.

It includes the following:

- Carer identification
- Hospital discharge and unpaid carers
- Social prescribing for unpaid carers
- Carer contingency planning
- Supporting unpaid carers through virtual wards
- Integrated Care Systems (ICSs) engagement of unpaid carers
- Carers' breaks
- Carers' assessments



### **Carer identification**



The identification of unpaid carers is essential for ensuring that people understand and can access support for their physical, mental, and emotional wellbeing. Identifying as a carer also enables people to engage with relevant health and social care systems and processes, such as hospital discharge, and helps to improve policy making.

Carers UK's State of Caring survey found that half (51%) of carers said it took over a year to recognise their caring role, with over a third (36%) taking over three years to do so.<sup>10</sup>

Health and care professionals are essential in helping family members and friends identify as unpaid carers, supporting them to navigate an often confusing pathway between the NHS and social care, and connecting them to the most appropriate support.

Several resources have been developed by NHS England, the Carers Partnership, and others to support the identification of unpaid carers across health and social care, including the following:

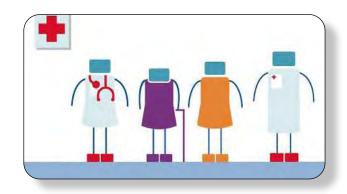
Supporting carers in general practice: a framework of quality markers

This NHS England resource is designed to improve carer identification in general practice. It includes practical ideas and actions to help GPs better identify and support carers of all ages. Its overall aim is to develop quality markers for Carer Friendly GP practice, to reduce carer breakdown and improve carer health-related quality of life. Participation by GP practices is voluntary and can be promoted and supported at Integrated Care System, Primary Care Network or individual practice level.

NOTE: This resource is being updated by NHS England in 2025.

### Carers passports in hospitals

A Carer Passport in a hospital is a simple tool which helps to identify and recognises someone as a carer for a patient in their hospital. The Carers Passport allows the carer to be more involved in the patient's care and connects them to additional support. The <u>video</u> below explains how a Carer Passport scheme in your hospital could benefit you.



You can find more information about Carers Passports **here**.

### **Carer identification**



### SNOMED CT codes – coding unpaid carers

NHS England has produced guidance on recommended Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) codes for unpaid carers of all ages, to ensure that carers are identified and supported across and within systems. Using SNOMED CT ensures consistent and accurate recording of clinical data and helps systems to report the number of unpaid carers who are registered in primary care, including young carers, and how many have

a carer contingency plan. You can find more information about SNOMED codes for carers **here**.

### Carers UK webpage on identification

Aimed at carers, this resource details ways in which carers can identify themselves and also highlights national awareness campaigns such as **Carers Week** and **Carers Rights Day** which we encourage all health and care professionals to support.

Good practice example

### **Bristol and South Gloucestershire Carers Support Centre**

GP practices in Bristol and South Gloucestershire have a broad and integrated approach to the identification of carers, across 26 GP practices in South Gloucestershire and 54 GP practices in Bristol. Some of the initiatives used to help support the identification of unpaid carers include:

- > A GP Link Volunteer programme.
- > Information to support carers to self-identify.
- > Carer awareness training at GP practices.
- > Carers registers.
- > Carers surgeries.

### Hospital discharge and unpaid carers



When supporting someone to be discharged from hospital, local authorities and NHS Trusts have a legal requirement to consider what support people are going to need at home, and who will provide that care.

Deciding to care, or continue caring, for someone leaving hospital can be challenging, especially for new carers or those whose caring responsibilities have increased or changed. A needs assessment for unpaid carers should therefore be undertaken to determine if they are willing and able to provide care, ensuring carers have a choice. Carers are entitled to support, ranging from advice and personal budgets to additional services for the person they care for.

# Legal responsibilities regarding carers at hospital discharge

As health and care professionals, you will be delivering your organisation's statutory duty under Section 91 of the Health and Care Act 2022 to *involve carers* where appropriate, in planning for hospital discharge as soon as is feasible.

This is supported by statutory guidance which specifies that NHS bodies and local authorities should ensure that, where appropriate, unpaid carers and family members are involved in discharge decisions.



### Hospital discharge and unpaid carers



# NHS London Hospital Discharge Toolkit

NHS London has developed a Carers and Hospital Discharge Toolkit to improve the experiences of carers and the people they care for during hospital discharge. Designed for London hospitals and community providers, the co-produced resource provides action-orientated top tips rooted in the legislative duties, statutory guidance and good practice to better support carers when someone they care for is being discharged from hospital. **Download the toolkit here.** 

### Coming out of hospital checklist and factsheet

Carers UK has produced resources and further information to support unpaid carers when they are supporting the person they care for at hospital discharge. These include a 'Coming out of hospital checklist' and a comprehensive 'Coming out of hospital factsheet'.

# Good practice example

### **Camden Carers**

In 2023, Camden Carers received funding for a Hospital and GP Development Project to support carers in hospitals, and after discharge. So far, they have distributed £4,999 in grants to 38 carers. These grants have been used to pay for things such as respite breaks, energy bills, and travel to and from hospitals.

After six-months, Camden Carers asked carers to provide feedback on the

efficacy of the grant. So far, 13 carers have provided feedback. 100% of these carers said the support they'd received through the grant had improved their wellbeing and had supported them in their caring role.

Camden Carers have also helped to co-produce the Carers Action Plan with carers, in partnership with Camden Council.

### Social prescribing for unpaid carers



Social prescribing helps support unpaid carers to stay healthy, well and connected to their community. It works particularly well for unpaid carers who are feeling lonely or isolated, experiencing poor mental health, have long term conditions or complex social needs.

By connecting people to practical, social and emotional community support, carers can access a wide range of community groups, activities, and services that support them with issues that affect their health and wellbeing.

**NHS England » Social prescribing** 

outlines that since 2022/23, as part of their contract, Primary Care Networks have been required to deliver proactive social prescribing services. This means that primary care networks must work with a population experiencing health inequalities to proactively offer social prescribing interventions. Local areas can use population health management data and the health inequalities improvement dashboard, alongside working with their local communities to identify who in their areas is experiencing health inequalities. Many PCN's have identified unpaid carers as a group that should be offered social prescribing.

Health and care professionals can support carers to access local social prescribing though their GP practice or through support offered by voluntary, community or social enterprise organisations.



### Social prescribing for unpaid carers



# Carers Partnership resources to support social prescribing:

- A resource for people working in local carer organisations, which explains what social prescribing is and how it can help unpaid carers.
- Top tips resource which is intended to support commissioners and providers who want to develop and enhance their social prescribing offer. It highlights the success factors in social prescribing schemes and interventions that combat loneliness.
- Examples of current good practice
  in social prescribing and interventions
  that combat loneliness for carers,
  particularly for communities who
  face additional barriers to accessing
  services (e.g. LGBTQ+ and ethnic
  minority communities).

# Good practice example

### **Sefton Carers Centre's The Listening Ear service**

The Listening Ear project is an emotional support service provided by Sefton Carers Centre to adult carers who experience isolation or would benefit from someone to talk to. The Listening Ear Service creates a safe and supportive space for carers to share their experiences and feelings and enables adult carers to talk through the challenges they face in their caring roles.

This type of listening service can be delivered as a standalone service or as follow-up support after counselling sessions. The flexible approach to deliver

enables carers to receive tailored emotional support based on their individual needs.

Benefits from this project include reduced carer isolation and stress. Listening Ear services can also serve as an early intervention measure, helping carers access support before their challenges escalate and connect them to relevant services where possible.

An average of 2780 carers have accessed this service per year since it was launched in 2009.

### **Carer contingency planning**



The NHS Long Term Plan, published in 2019, makes clear that identifying, recognising and supporting carers is a system priority. This includes supporting carers in emergencies; and for this to be effective, carers need to make contingency plans for if/when they are unable to provide care (in some areas referred to as emergency plans).

For effective contingency planning, carers need to understand the benefits of making a contingency plan and what support is available. It is also essential that health and care teams are aware of how to find existing plans, know how to activate them promptly when required, and feel confident to have meaningful conversations with carers.

Contingency planning for carers can vary within and between systems, but in 2021/22 NHS England supported integrated care systems (ICSs) to scope the delivery of carer contingency planning. Insights from ICS-led projects and their recommendations, along with links to case studies, are outlined **here**.

The report recommends that all ICSs need to take steps to:

- understand current contingency planning provision in the system,
- determine routes for information sharing,
- train professionals,
- communicate what is available to both carers and professionals, and measure to determine impact.

Carer contingency plans are designed to ensure that individuals with care needs continue to receive support when the unpaid carer cannot care or provide the same level of care as usual. They outline the key information and essential actions to take in these circumstances.

### **Carer contingency planning**



# Resources to support health and care professionals with effective carer contingency planning:

- Carer Contingency Campaign Pack:
   The Carers Partnership worked with NHS England in 2023/24 to develop a Carer Contingency Campaign Pack.
   The pack includes a toolkit of resources designed to support local carers organisations and others to deliver carer contingency plans for carers in their area.
- MyBackUp: Please use this simple tool to support unpaid carers to develop effective contingency plans that meet their needs and the needs of the person(s) they care for. Find out more here.
- Jointly: an innovative mobile and online app that is designed by carers for carers to help make caring feel less stressful and more organised. Please highlight the tool to any carers you come into contact with. Find out more here.

# Good practice example

### Carers First's 'Plan for the best' Emergency Plan

In 2022, Carers First launched a campaign to help unpaid carers understand the importance of planning for an emergency and to encourage them to put an emergency plan in place.

Working collaboratively with carers, Carers First gathered insights on the barriers to having an emergency plan including misunderstandings about what an emergency plan is or why it was needed and 'not knowing where to start'.

To address these challenges, Carers First developed a practical emergency planning toolkit which includes a downloadable template with guide and a physical pack.

#### Since the campaign

- > Over **2,300** templates accessed through the website.
- > Over **4,000** views on the Planning for Emergencies as a carer page.

Continuing this best practice, Carers First supports registered carers to prepare for emergencies, supporting them to access resources to ensure every carer has an Emergency Plan in place.

### **Supporting carers through virtual wards**



Virtual wards (also known as <u>Hospital</u> at <u>Home</u>) allow patients to get hospital-level care safely at home and in familiar surroundings. The staff, equipment, technologies, medication, and skills usually provided in hospital are delivered in people's own homes.

# Legal requirements to involve and support unpaid carers through virtual wards

Under the Health and Care Act 2022 (Section 25, amending Health Act 2006), each Integrated Care Board (ICB) has a duty to promote the involvement of patients and their carers in any decisions which relate to the prevention or diagnosis of illness in the patients, or their care or treatment.

In practice terms this means:

- Ensuring that the contributions of carers are properly acknowledged and valued when it comes to planning and providing care.
- Being proactive in communicating with carers, ensuring that they are kept well informed throughout the process from planning care, to implementation, and ensuring that there is correct follow-up after the use of a virtual ward ceases.
- Training and information should be provided for staff involved in the delivery of the virtual ward so that they can better understand the needs of unpaid carers, and ensure they fulfil their duties towards them.

### The NHS England operational framework for virtual wards

(published August 2024) highlights that unpaid carers should be recognised as equal partners in care who can provide vital information about the person with care and support needs.

The framework makes clear (appendix 2) that to support carers, virtual wards must be designed in such a way that enables professionals to:

- · identify unpaid carers,
- signpost carers to carers' assessments and further support, such as advocacy and respite care,
- involve carers as equal and expert partners in care,
- be aware of carer rights under the Care Act and young carer rights under the Children and Families Act,

### **Supporting carers through virtual wards**



- have informed discussions with carers about the choices available for care and their right to choose the level of care they provide, including no care if they are unable or unwilling to provide any care,
- ensure that carers have access to information about what to do if: they are no longer able to provide care on a virtual ward or their needs or those of the person receiving care increase.

Resources for health professionals to help them support carers in the delivery of virtual wards:

# Virtual wards toolkit – 'Getting it right for unpaid carers'

The Carers Partnership has worked with the virtual wards team at NHS England to develop a suite of resources to support the delivery of virtual wards in England, ensuring they consider and engage with unpaid carers.

This co-produced toolkit is aimed at professionals, local carer organisations, local authorities and unpaid carers. It includes information on virtual wards and resources we have developed through our work with NHS England and the Health and Wellbeing Alliance including:

#### Professionals' checklist

This co-produced resource helps virtual wards teams to support consistent practice in the identification, involvement and support of unpaid carers who interact with virtual wards.

### Carer pathway

Aimed at professionals involved in the delivery of virtual wards, this co-produced resource outlines the journey a carer will take when they are asked to care for someone on a virtual ward. Carers' checklist for virtual wards

This checklist was developed as a guide with and for carers, so that they can better understand what to expect if they choose to care for someone on a virtual ward. It includes a checklist of the questions they should ask, or expect to be asked.

- Policy briefing on virtual wards and what they mean for unpaid carers
   Aimed at local carers organisations and unpaid carers, it provides information on what virtual wards are, why they have been established, and what they mean for unpaid carers and local carer organisations.
- Carer information leaflet for local carers organisations

To be used as a template by local organisations to provide carers with information about virtual wards.

### Integrated Care Systems (ICSs) engagement of unpaid carers



Integrated Care Systems are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.

The statutory bodies that comprise Integrated Care Systems (i.e., Integrated Care Partnerships and Integrated Care Boards) have statutory duties towards carers, as set out in the Health and Care Act 2022, which mean they have a legal responsibility to:

 Involve unpaid carers alongside patients and the public in relation to planning, commissioning and operational changes of services that relate to them (s. 25 14Z45 Health and Care Act 2022).

This means that if strategies or services are being created or changed, then unpaid carers should be involved. It is essential that unpaid carers are mentioned specifically in involvement and consultation and the way that this is done is critical to

- ensure that carers' experiences are understood. There is guidance on engagement for ICSs more generally which we set out below.
- Promote unpaid carers' individual involvement (where appropriate) in a patient's prevention, diagnosis, treatment and care (section 25 14Z36 of the Health and Care Act 2022 which amends the 2006 Act). Integrated Care Boards must promote this through all providers of services e.g. NHS Trusts (hospitals) and GP practices.

The Carers Partnership has worked with NHS England to develop resources to support ICS engagement with unpaid carers and ensure they are meeting their statutory duties. These resources include:

ICS policy explainer

This resource is aimed at unpaid carers and local carers organisations, to provide information as to what ICSs, ICBs, and ICPs are and how they relate to unpaid carers. It provides

information about how these structures fit with others in health and social care, the role Voluntary, Community, and Social Enterprise (VCSE) organisations play, as well as how to find out information about their local ICB/ICS.

#### Carer engagement guide

This resource, co-produced with unpaid carers, provides an overview of ICSs, including the background to their formation, what their legal responsibilities towards carers are, and the types of services and systems that fall under them. The resource also talks about the potential challenges of engaging with ICSs, and how carers can effectively engage with them, and which structures they can do so through.

### Carers' breaks



Carers' breaks are essential in helping people to continue caring while maintaining their own health and wellbeing, social connections and relationships.

Being able to take time away from the pressures of a caring role is one of the most frequently voiced concerns from unpaid carers. Despite this, access to breaks can be difficult and many carers simply do not get the breaks they need; 41% of carers recently told Carers UK they have not taken a break in the last year.<sup>11</sup>

Carers' breaks should be planned, meaningful and positive. The National Institute for Health and Care Excellence (NICE) recommends that carers' breaks should "meet carers' needs for a break, for example in duration, timing, frequency and type of break" and "be arranged in a way that provides reliable

and consistent support to the carer". The arrangements therefore need to work for both the carer and the person they care for, in order to be beneficial and improve carer wellbeing.

Time Away From Caring: Good Practice in Carer Breaks, is a report and resource developed by the Carers Partnership for commissioners and providers who want to develop and enhance their carer breaks offer. It:

- brings together evidence on the importance of breaks for unpaid carers,
- highlights good practice in providing breaks and,
- offers top tips to commissioners and providers on what steps they can take to ensure the carers they support have access to breaks.



#### Carers' breaks



# Other resources to support better understanding of carers' breaks

- The Social Care Institute of
  Excellence (SCIE) has produced
  guidance for commissioners,
  providers and others involved in the
  planning, shaping and delivery of
  support for adult carers, primarily
  in England. It will be of interest to
  commissioners within local authorities
  (including public health), integrated
  care systems (ICSs), NHS trusts and
  mental health trusts.
- Carers UK's Taking a break factsheet is a resource which health professionals can share with carers on breaks and respite. It provides information on the importance of breaks, how to arrange replacement care and plan breaks, ways to find support with the cost of a break and the potential implications breaks may have on social security benefits that many carers access.
- Carers UK's Supporting carers
   to take a break video series
   contains interviews with carers about
   their experiences accessing and
   organising breaks, where they have
   found support from, and how it has
   helped them. These videos are aimed
   at unpaid carers as a way of advising
   them on how to access breaks, using
   the voices of carers themselves

Good practice example

# Wandsworth Carers Centre – Partnership working with organisations and carers

Wandsworth Carers Centre partnered with Blue Bird Care – a private care company– to give carers a break. This service is designed to enable carers to take short breaks away from their caring role by providing respite care. It is aimed at carers who may not have the financial resources to access private care and/or carers who do not have family or close friends nearby who can cover their care.

Carers can access 52 hours of breaks over nine months free of charge.
Carers can use the hours flexibly within the nine months and the service is accessible seven days per week, except for Bank Holidays.

In 2024, Wandsworth Carers Centre connected 84 unpaid carers to Blue Bird Care to access a respite break.

### Carers' assessments



Under Section 10 of the Care Act 2014, local authorities must assess unpaid carers to identify their personal outcomes, current and potential needs, and the impact of their caring role on their wellbeing.

Health and social care professionals have a key role in helping carers access and engage with these assessments. This includes informing carers of their rights, explaining the purpose of the assessment, and providing clear guidance on the process.

Professionals conducting the assessment must create a supportive environment, empowering carers to share their needs and priorities. Using strengths-based approaches, they can facilitate meaningful conversations and explore the carer's existing resources and challenges.

Assessments should evaluate whether carers are willing and able to continue their role and determine the support required to sustain it. They must also account for the fluctuating nature of carers' needs, considering both present circumstances and potential future changes.

Once completed, the assessment should provide a comprehensive understanding of the carer's situation, ensuring appropriate support is identified. Where eligible needs are found, professionals should work to secure support that makes the carer's role both sustainable and aligned with their wellbeing and personal outcomes.

# Carers' assessments – developments, digital, diversity, co-production and good practice

This resource is aimed at local authorities and local carer organisations and is intended to increase awareness around what carers' assessments entail from a carer's perspective. It also highlights what further support can be offered in terms of accessing assessments and the support that follows. It also includes good practice examples of innovative delivery regarding carers' assessments.

### **Legislation and further resources**

You can access further information about the importance of carers' assessments using the resources below.

Care Act: Legal duties and impact on individuals (SCIE, 2024)

NICE guideline: Supporting adult carers (NICE, 2020)

Advice for unpaid carers on carers' assessments (Carers UK)

# Annex 1: Legal duties to unpaid carers across health and social care

There are several legal responsibilities set out in statute that exist across health and social care regarding unpaid carers.

A legal responsibility is an obligation placed on an organisation or individual to undertake duties which are set out in legislation. Most health and care legislation places responsibilities on organisations, but the people working within those organisations deliver these responsibilities.

Examples of legislation which include duties to carers include:

- Health and Care Act 2022
- Care Act 2014
- Children and Families Act 2014
- Carer's Leave Act 2023 and other employment rights legislation
- Equality Act 2010
- Human Rights Act 1998

Legislation is often supported by statutory policy guidance which provides further explanations of legal duties or expectations. This statutory guidance is seen has having the force of law.

As professionals who are likely to be in contact with carers, it is important that you know what legal duties and responsibilities are in place, to ensure you are offering carers the support they are entitled to under various legislation.



### Annex 1: Legal duties to unpaid carers across health and social care

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

The Health and Care Act 2022 came into force on 1 July 2022 in England and has four key provisions in relation to unpaid carers:

- Section 10: Places a duty on NHS
   England to consult carers and other relevant representatives affecting commissioning or policy decisions affecting services.
- Section 25: Places a duty on Integrated Care Boards to promote the involvement of each carer, where appropriate, in relation to decisions about prevention, diagnosis, treatment and care.
- Section 25: Places a duty on Integrated Care Boards to consult carers in commissioning or policy decisions affecting services.
- Section 91: Places a duty on NHS
   Trusts and Foundation Trusts to
   involve carers, where appropriate,
   in planning for hospital discharge
   as soon as is feasible.

Practically, this means that unpaid carers should be consulted about changes to health services, and involved by health services, where appropriate, in the prevention, diagnosis, treatment and care of the person they care for. They should also be involved as early as possible, where appropriate, in the planning for hospital discharge if the person they are caring for is likely to need care following a stay in hospital. Their ability to provide and continue to provide care should also be considered - this means both a choice about caring. or elements of caring and what help, learning or information they might need to do so.

As a result, health and care services should be proactive in identifying carers, be clear with carers what rights and entitlements they have, work proactively with the voluntary sector, carers and with local authorities, and check that systems and processes are working well by regularly checking with carers and getting feedback from people experiencing the system.

You can find more detail about what the Health and Care Act 2022 means for unpaid carers <u>here</u>.

#### The Care Act 2014

The Care Act 2014 requires local authorities to assess, provide support, and promote the wellbeing of unpaid carers. This includes providing information and advice, and preventing, delaying or reducing further needs from developing. Local councils also have a duty to involve unpaid carers in the design of services that affect them.

The specific provisions of the Care Act in relation to carers include:

 Carer's assessment: Unpaid carers can have an assessment of their needs, which is separate from the assessment of the person they are caring for. This assessment can help identify the support services the carer might need, including training, or respite care.

### Annex 1: Legal duties to unpaid carers across health and social care

- Right to support: If any carer's
   assessment identifies eligible needs,
   local authorities are required to
   provide support to help the carer
   manage their caring responsibilities.
   This can include practical
   support, information, or access to
   community services.
- Access to information about support:
   Local authorities and health services
   are required to provide information
   and advice to carers about available
   services and support options.

The following links provide more information about unpaid carers and the Care Act 2014:

- carersuk.org/help-and-advice/ guides-and-tools/your-guide-tothe-care-act-england
- local.gov.uk/publications/care-act-2014-and-unpaid-carers-handysummary
- carers.org/carers-and-the-law/thecare-act-2014

# The Children and Families Act 2014

The Children and Families Act 2014 came into force in April 2015. The Act protects children, as well as offering specific protection to young carers and parent-carers of disabled children (including those with a long-term condition).

The Act sets out that local authorities must meet their duties to identify, assess and support young carers, young adult carers and their families. They need to work with other local organisations to make sure they proactively identify all young carers. They must also make sure the assessment process meets the criteria set out in the legislation. They must also make sure that they join up the work of children's services and adult services so that young carers and young adult carers benefit from professionals working together.

You can find out more information about the Children and Families Act 2014 and the impact it has on young carers, young adult carers, and their families, **here**.

Information on parent carers' rights under the Children and Families Act 2014 can be found **here**.

### Rights at work

There are a variety of rights that unpaid carers have in the workplace if they are employed. These include a right to take time off for emergencies for dependents, a right to request flexible working and a right to take unpaid Carer's Leave for up to five days per year. Carers UK has produced comprehensive information on carers' workplace rights **here**.

### Annex 1: Legal duties to unpaid carers across health and social care

### **The Carer's Leave Act 2023**

The Carer's Leave Act 2023 came into force in April 2024 and makes provision for employees who balance work with caring responsibilities to take up to one week of unpaid carer's 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. This leave is available from the first day of employment and it provides the same employment protections to employees as other forms of family-related leave, including protection from dismissal.

It is important that health and care professionals are aware of this legislation – firstly because of the impact that providing care can have on people's ability to stay in work, but also because many health and care professionals are themselves unpaid carers – indeed, a recent NHS Staff Survey found that 1 in 3 NHS staff provide care to a family member or friend. You can find more information about the Carer's Leave Act 2023 here.

### The Equality Act 2010

The Equality Act 2010 protects people who are looking after someone who is elderly or disabled against direct discrimination or harassment because of their caring responsibilities. This is because they are counted as being 'associated' with someone who is protected by the law because of their age or disability. You can find more information **here**.

The Government Equalities Office and Citizen's Advice Bureau has also produced a guide which is intended to help carers understand how the Equality Act can help them. You can download this guide **here**.

### **The Human Rights Act 1998**

Article 8 of the Human Rights Act protects the right to family and private life, which can be relevant to unpaid carers. If a local authority doesn't provide adequate support, such as respite care or a carer's assessment, this could violate an individual's Article 8 rights.

**The British Institute of Human Rights** has developed this guide which provides practical information on how the Human Rights Act is relevant to carers and those they care for. It outlines and explains carers' human rights, as protected by the Human Rights Act 1998 and the Equality Act 2010. It helps carers understand how human rights relate to their caring role, and how they can be used to stand up for their rights and the rights of those they care for. It includes accessible explanations of the law, examples and real case studies, to show how human rights can empower people in their discussions with public services.

For more information about carers' rights, please access the resources Carers UK has created for unpaid carers.

### About the VCSE Health and Wellbeing Alliance

The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) is a partnership between voluntary sector representatives and the health and care system.

It is a key element of the Health and Wellbeing Programme, enabling the voluntary sector to share its expertise at a national level to improve services for communities who experience inequalities and/or exclusion. Its purpose is to:

- Provide a co-ordinated route for health and care organisations to reach a wide range of VCSE organisations.
- Support collaboration between VCSE organisations and provide a collective voice for issues related to VCSE partnerships in health and care.

- Enable health and care organisations and VCSE organisations to jointly improve ways of delivering services which are accessible to everyone by making it easier for all communities to access services which reduce health inequalities.
- Ensure health and care decisionmakers hear the views of communities which experience the greatest health inequalities.
- Bring the expertise of the VCSE sector and communities they work with into national policy making.

Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society. Find out more about health inequalities <u>here</u>.

### The Carers Partnership's work through the Health and Wellbeing Alliance aims to:

- Improve knowledge of barriers and enablers regarding unpaid carers' access to services amongst health and social care professionals, commissioners and policy makers.
- Increase uptake of resources by unpaid carers and the professionals who support them, across both health and social care, helping to improve carers' access to support and their understanding of local support available.
- Support providers and policy makers to include and systematically think about unpaid carers when it comes to service design and improvement – at both national and local levels.
- Increase sharing of knowledge about 'what works' when it comes to supporting unpaid carers across both health and social care.

### References

- 1 Census 2021
- Petrillo, M., Zhang, J., and Bennett, M.R. (2024) Valuing Carers 2021/2022: the value of unpaid care in the UK. London: Carers UK. carersuk.org/reports/valuing-carers
- 3 gov.uk/government/publications/caring-as-a-social-determinant-of-health-review-of-evidence
- 4 ons.gov.uk/releases/unpaidcareexpectancyinenglandandwales
- 5 Carers UK analysis of the GP Patient Survey 2024
- 6 adult-carer-survey-report-2023--full-uk-report-(english).pdf
- 7 Carers UK (2023) State of Caring: the impact of caring on health
- 8 Carers UK (2022) State of Caring 2022
- 9 adass.org.uk/documents/adass-spring-survey-2024
- 10 Carers UK (2022) State of Caring 2022
- 11 Ibid







Carers Trust works to transform the lives of unpaid carers. It partners with its UK-wide network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes, raise awareness, and influence policy. Carers Trust's vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

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Across the UK today 5.8 million people are carers – supporting a loved one who is older, disabled or seriously ill. Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community. We're here to make life better for carers.

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The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance is jointly managed by the Department of Health and Social Care (DHSC), the UK Health Security Agency (UKHSA) and NHS England and is made up of 18 VCSE Members that represent communities who share protected characteristics or that experience health inequalities and a VCSE coordinator. Through their networks, HW Alliance Members link with communities and VCSE organisations across England.

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