

Please note: The strategy now covers up to and including December 2021 due to COVID-19.

## Definition of a carer

**“A carer is someone of any age who looks after a child, relative, partner or friend in need of help because they have an illness, disability, frailty or a substance misuse problem.**

**The care they provide may be personal, emotional or supervisory and is unpaid”**

(i.e. the definition does not include those employed as care workers).

**Adult Carers** are adults caring for adults over the age of 18. This includes adults caring for their adult children.

**Parent Carers** are parents caring for a disabled child or young person under the age of 18.

**Young Carers** are children and young people under the age of 18 who support a family member or friend.

**Hidden Carers** do not identify themselves as carers and therefore may not seek support and information that would benefit them. In particular, difficulties in identifying individuals in some specific groups can incorrectly lead to the belief that these individuals do not need or want services or support. Although we know there are hidden carers across all carer groups, the following groups are acknowledged as being harder to reach:

- Carers from minority ethnic backgrounds
- Carers with mental health problems including those with dementia
- Carers who are lesbian, gay, bisexual or transgender
- Carers who look after someone with a drug or alcohol problem

## National Key Facts (Carers Trust 2016)

- There are around **7 million** carers in the UK – **1 in 10** of the population (**42%** of carers are men and **58%** are women).
- **3 in 5** people in the UK will be carers at some point in their lives.
- It is estimated that there are **700,000** young carers in the UK.
- There are **4.27 million** carers of working age living in the UK (Nearly **1 in 8** workers).
- **1 in 5** carers gives up employment to care.
- Carers providing more than **50** hours of care per week are twice as likely to report ill-health as those not providing care.
- The economic value of the contribution made by carers in the UK is **£132bn** a year.

## North East Lincolnshire Key Facts

- It is estimated that there are **15,993** carers in NEL.
- It is estimated that there are over **700** young carers in NEL.
- **1,826** adult carers, **360** parent carers and **32** young carers are registered at the NEL Carers Support Service.
- **126** parent carers are registered with an open case in Children's Services.
- **595** adult carers are assessed within Adult Services.
- **258** young carers are registered with the Young Carers' Support Service.
- It is estimated that carers in NEL save the local economy **£309** million a year (*Valuing Carers, Carers UK 2015*).

## Introduction

Welcome to the 2017-21 North East Lincolnshire (NEL) Carers' Strategy, Vision and Forward View. Its aims are to reflect the national carers' agenda, support the needs of local carers, further embed the carers' agenda within core health and social care practice, and continue to forge a true multi-agency partnership across NEL which supports carers. This Strategy is led by NEL Clinical Commissioning Group (NELCCG) in partnership with North East Lincolnshire Council (NELC) and the NEL Carers' Strategy Group.

The first national Carers' Strategy "Caring about Carers, a National Strategy for Carers" was launched in 1999. Since then, there have been a number of national strategic updates, and legislation has been introduced to improve carers' rights via the Care Act 2014 and Children and Families Act 2014.

This Strategy has been informed by national and local guidelines, consultation, evidence and good practice. At the time of writing, publication of a revised national carers' strategy is awaited; in the interim we have drawn our themes from the latest available national strategy and adjusted it to reflect the local picture within NEL.

NELCCG is acutely aware of the dedication and commitment carers generously provide to those they care for, and the crucial contribution carers make to society. Without carers, our community would be economically and socially poorer. In recognition of this, and as part of our commitment to acknowledging carers as expert partners, this Strategy has been developed with significant contributions from local carers (consultation on the format of the initial information questionnaire, direct consultation on all areas of the strategy via workshops for all carer groups and finally, open public feedback on the draft strategy vision document). Between July 2016-January 2017, carers from all carer groups were asked to share their views on what is working well to support carers, what could be improved, what support matters most to them and what the priority areas for action are. Professionals were also invited to attend the carers' strategy workshop to give their views on carers' support and local priorities.

Once this Strategy was drafted, it was circulated for comment via carers' websites, and submitted to the NEL Carers' Forum and NEL Carers' Strategy Group for approval prior to formal sign off via NELCCG and NELC.

The Strategy consultation process highlighted further work required to improve the identification, recognition and services to support carers locally. All detailed gaps from this process have been fed into the priority setting section of the Strategy. This is underpinned by an action plan, which will be developed and monitored through the multi-agency NEL Carers' Strategy Group and Carers' Forum over the next 4 years.

### **Scope**

This Strategy covers all carers of any age in NEL and draws together partnership working under the multi-agency carers' agenda, including all aspects of carers' support from identification and recognition to support and services.

### **Our core achievements (2013-2016)**

- ✓ Further developed the multi-agency carers' strategy group and NEL carers' forums ensuring improved communication between all partners and greater identification, recognition and support for carers across NEL.
- ✓ Re-commissioned the Carers' Support Service to provide a fit for purpose hub of advice, information and support.
- ✓ Established and enhanced a greater range of local carer support and services.
- ✓ Further embedded carers' involvement in service redesign, implementation and staff recruitment.
- ✓ Ensured robust and continuous carer consultation to ensure services are designed around carers' needs.
- ✓ Integrated carers into key agendas (end of life and dementia), to improve carer recognition and involvement.
- ✓ Increased the overall number of carers identified, registered, informed and supported year on year (via NEL Carers' Support Service, GP carer registers and social care registers).
- ✓ Trained health and social care staff and wider community members on the Care Act and Children and Families Act with respect to carers, and further raised the profile of carers in NEL across these staff/community groups.
- ✓ Developed an extensive range of up to date carers' related literature which is widely distributed across NEL.
- ✓ Supported development of the Single Point of Access and Services4Me to ensure carers are well informed.
- ✓ Developed a wider offer for carers regarding wellbeing, learning and support.
- ✓ Ensured local support for key carers' events, such as Carers' Rights Day and Carers' Week.

### **The following vision has been developed for carers in North East Lincolnshire:**

Our vision for North East Lincolnshire is to ensure that all carers (adult, parent and young carers) are valued, recognised and supported to care and have a life outside of their caring role (based on identified needs and interests). Through partnership working, we will:

**Raise the profile of carers and the caring role within North East Lincolnshire (NEL) as a community**

**Provide access to quality information and support**

**Work to reduce the impact of caring on carers' wellbeing**

**Work with carers and local partners to develop strong networks**

**Challenge inequality, and ensure that carers of all ages and backgrounds have the opportunity to make their voice heard**

**Ensure that the development of preventative and early interventions for carers is supported**

**Influence society to improve the lives of carers**

In order to achieve the vision our Forward View will be separated into key local carer themes as follows:

1. Carers are identified at the right time
2. Carers are provided with appropriate advice and information throughout their caring journey
3. Carers needs are identified and responded to appropriately
4. Carers are supported in their caring role and have a life outside of caring and beyond it
5. Carers are recognised as expert care partners and are involved in care and support planning for the cared for
6. Carers are involved in service design, delivery and monitoring

# Priority Setting

## Carers are identified at the right time

### Gaps identified during consultation

- Further increase the use of the media and publicity materials to reach and inform hidden carers about the support available - social media, posters and news articles.
- A reduction in the use of the term “carers” is required as this is often a barrier to identification (carers do not see themselves as carers).
- Further improvement in carer identification and provision of support is required at times of crisis for carers of those with life limiting conditions.
- Improved awareness of carer groups is required among professionals (i.e. young, sibling, parent and adult carers).
- Expansion of the identification of young carers in particular is required across the health and social care system.
- Further identification and recognition of all carers, needs and roles as expert care partners by all professionals, especially health and social care.
- Greater awareness of carers is required across the wider NEL community (hairdressers, libraries, police etc.).
- The carer role, issues and available support needs to be a standard part of education for young people.
- Improved carer identification is required for carers of those with substance misuse problems.
- Employers need to further develop their identification of carers and signposting facilities.
- Carers' champions are required in all areas (health, social care, education) to improve carer identification.

### Carer Champions

- Establish carers' champions across NEL – i.e. within GP surgeries, hospital, education and local employers where possible.

## Areas for Action

### Wider Community Awareness

- Ensure all carers identified by any means, or who present themselves, will be informed of their rights as a carer.
- Continue to focus on seldom heard groups, in order to identify a greater number of hidden carers, such as males, young adult carers, carers from black, Asian and minority ethnic groups and carers who are lesbian, gay, bisexual or transgender.
- Deliver a yearly programme of events relating to the national themes during Carers' Week and Carers' Rights Day to ensure wider recognition and support to carers across the community.
- Work with local employers to understand the role of carers, encourage adoption of supportive carer policies and a shift in culture that will help carers to continue working while caring.
- Deliver a programme of on-going monthly awareness raising activities within the NEL community to encourage the identification of all carers and promote NEL as a carer friendly community.

### Carer Identification and Registration

- Increase the number of
  - carers registered at the NEL Carers' Support Service;
  - adult carers known to/registered within social care;
  - parent carers known to/registered with Children's Services;
  - young carers identified via Young Carers' Support Service;
  - all carers registered within Primary Care (GP Carers' Register);
  - all carers identified within Secondary Care.

### Training and awareness raising

- Ensure a rolling carer training programme is delivered in domiciliary care, care homes, clinical and care settings which covers the responsibilities of each individual to identify and signpost all carers to support, plus the benefits of doing so.
- Ensure a rolling programme of training/awareness in education (primary, secondary, higher and further education) in NEL regarding the issues facing all carers and staff, including the responsibility to identify, signpost and support carers.
- Develop and deliver a programme of training/awareness across employers in NEL regarding all aspects of the carers' role.

# Carers are provided with appropriate advice and information throughout their caring journey

## Gaps identified during consultation

- Information and advice needs to be more readily available, visible, easier to find and more accessible (i.e. one hub of all carer related information that is constantly updated. Information sessions provided at times to support working carers).
- There needs to be improved information provision on:
  - specific medical conditions, condition progression and needs of the cared for to ensure the carer appropriately understands the cared for person's needs and what their caring role is likely to entail;
  - carers' support available at the point of diagnosis/discharge from hospital;
  - transition between children and adult services.
- The language used in advice and information needs to focus less on "carers" and more about the role of a carer, as not all carers see themselves as „carers“.
- Information needs to be more timely.
- Further improved signposting from health care professionals is required to ensure carers have access to appropriate advice and information.
- Greater use of community venues to provide information to carers is required to raise awareness of carers and the support available.
- Further develop the information available on the "carers' needs assessment"– i.e. creation of a specific leaflet that is used across all services.

## Areas for Action

### **Provision of up to date, accessible and timely advice and information.**

- Continue to develop (where necessary), review and update carer related information; ensure there is a visible and accessible range of quality information for carers through a wide variety of mechanisms and formats to help carers recognise themselves as carers and inform them throughout their caring role.
- Provide clear information on the transition between children and adult services.
- Develop a specific leaflet on carers' needs assessments.
- Research into ways to tailor information to reach and inform hidden carers.
- Explore the potential for the production of a "Carer's Passport" or other document which would easily identify carers and confirm consent to share information with them relating to their cared for person.
- Continue to work in a multi-agency way to deliver on an on-going basis the Carers' Health and Wellbeing Outreach Campaign to ensure carers have access to a wider range of carer related advice and information.
- Continue to work in partnership across NEL to ensure health and social care organisations and wider community outlets have carer specific information accessible via boards/websites/information areas and within their standard information packs to ensure carer information is visible and accessible across NEL.
- Ensure health and social care professionals provide relevant specific information/advice on caring and (with consent) information pertaining to the cared for person at all key points in a caring journey.
- Further develop the NEL Carers' Support Service (CSS) as the single central hub for carers, which summarises carer support/information/advice and links to organisations and their websites, to make it easier for carers to navigate the system.

### **Ensure front line staff in a range of settings are kept well informed on carers needs, assessments and how to signpost to appropriate services.**

- Delivery of carers' awareness sessions to professionals and community groups identified across the community, to enable them to provide accurate, timely and appropriate advice and information to carers throughout their caring journey. At least one awareness session per month covering carers, carers' issues, carer rights and the support available.
- Undertake training with GP reception staff as a minimum on an annual basis, to embed carer registration practice in the process of joining the surgery/updating personal details and ensure GP surgery staff are aware of services to signpost carers to. All carers giving consent will be referred to their GP from NEL CSS and vice versa.

# Carers needs are identified and responded to appropriately

## Gaps identified during consultation

- Health and wider community care professionals need a greater understanding of carers to ensure carers' needs are identified and responded to.
- Greater consistency in quality of practice is required during carers' needs assessments.
- Continued improvement is required in response to the needs of the carers, when the cared for person's level of services/support has been reduced.
- Equal attention is needed when identifying and responding to the carers' needs and those of the cared for.
- Further embed recognition and appreciation of "all carers needs" when the carer is caring for more than one person, particularly where this crosses two organisations e.g. social care and mental health services.
- Continued awareness/identification of carers' needs at the point of applying for Carers Allowance/other benefits to ensure appropriate signposting to respond to those needs accordingly.
- Referring to carer "needs" can be off putting as it suggests that the carer isn't coping/ managing.

### Carers' needs are identified

- Ensure health and wider community care professionals have an improved understanding of carers and carers' issues to ensure carers' needs are identified.
- Ensure greater partnership working with wider agencies.
- Ensure greater awareness and identification of the full suite of carers' needs when the carer is caring for more than one person.
- Develop proactive support mechanisms to enable carers to plan for their post caring needs.

### Areas for Action

### Carers' needs are accessed where appropriate

- Ensure carers who present with an appearance of need are offered a carer's/combined needs assessment.
- Ensure 100% of assessed adult carers have an initial 6 week review.
- Ensure 100% of assessed adult carers needs are appropriately reviewed on an on-going basis and at least annually.
- Ensure parent carers' needs are identified, assessed and reviewed where appropriate.
- Ensure young carers' needs are identified, assessed and reviewed where appropriate.
- Work to ensure greater consistency in quality of practice in the delivery of carers' assessments.
- Ensure carers crisis/emergency planning is a key part of the carers' needs assessment.

# Carers are supported in their caring role and have a life outside of caring and beyond it

## Gaps identified during consultation

### Carers' support

- Greater professional support within the family is required to remove the stigma of carers accessing support.
- Continue to expand the availability of carers' support outside of working hours to support working carers.
- Further embed a consistent offer of vital emotional support to carers, whether this is early support in adjusting to the caring role, support with feelings regarding a specific cared for person's condition, support to maintain family relationships (e.g. parent with a non-cared for child), after or during the bereavement process or support to enable the carer to admit a need for help.
- Greater continuity and flexibility of support is needed during periods of transition and crisis.
- A resource, such as a "carer time bank" needs to be developed to counteract a decreasing social circle, improve social interaction and provide carers with an opportunity to share/learn skills.
- Further development of "friendship groups" led by carers is required to promote social interaction and friendships.
- Continued improvement in support for carers whose cared for person has lost/seen a reduction in services, or where financial contribution to service costs have increased.
- Improved support is required after bereavement.
- A broader awareness of carer specific issues is required among professionals (i.e. carers' health and wellbeing, the need for flexible appointments/dedicated support and breaks at specific times throughout the caring journey).

## **Carers' breaks**

- The process to access respite needs to be streamlined and improved to ensure speed of access and reduce carer related anxiety/stress; respite contributions are also too costly.
- The process to access sitting services needs to be improved to ensure consistency of access and charging (dependent on whether the service is deemed for the cared for person/carer).
- Improved delivery of carers' breaks services is required.
- Respite, sitting services and childcare services need to be offered by those with appropriate skills/knowledge of conditions (e.g. physical disabilities).
- Services need to be more reliable and responsive, for example in emergencies.
- Development of a dedicated sitter service would be beneficial so that carers can attend carers' support services or time limited/one off activities.
- Increased flexibility and reliability is required in carers' breaks services to accommodate working carers.

## **Carers' health**

- Greater recognition from professionals is required of carers' health, in particular relating to their caring role.
- Further improvement in the recognition of the carer is required during health appointments for the cared for person, i.e. improved identification of the carer and signposting to support and services.

## **Support for young carers**

- Greater awareness, acknowledgement and flexibility is required in schools to allow young carers to concurrently manage specific issues relating to caring (sleep deprivation/time constraints/bullying) and their education.
- Further development of the offer of support is required for young carers of a disabled sibling.
- Further development of the offer of support from Children's Services is needed for parent and young carers (i.e. support with working options, sleep solutions, health concerns, family relationship awareness, young buddies, etc.).

## **Employment, education and training**

- Greater information provision and support is needed for carers to remain in or return to work. Further work is needed with employers to highlight the needs and benefits of a carer workforce.
- A greater range of carers' support/breaks to ensure carers can combine work with caring.

## **Financial**

- Greater range of financial support options for carers is required to ensure carers do not end up in poverty.

### **Carers' Support**

- Work to develop professional support for carers to remove the stigma within families of carers accessing support.
- Work to ensure greater availability and flexibility of all carers' support.
- Ensure appropriate support is available for carers whose cared for person has lost/seen a reduction in services.
- Look to develop a programme for carers to support each other, such as time banking, via a variety of mechanisms.
- Further increase the numbers of carers accessing universal carers' support services.
- Explore the transport options available to carers in NEL to access services and ensure information on transport is available to carers.
- Develop training on carer personal safety in the caring role.
- Further improve and develop pre and post bereavement support for carers.
- Support carers and former carers to access a variety of volunteering opportunities.

### **Areas for Action**

#### **Carers' Breaks**

- Streamline and improve the process to access carers' breaks (consistency of access/charging) for those with assessed needs to reduce carer related anxiety/stress.
- Work with carers' breaks services to ensure there is greater flexibility and reliability in service provision.

## Young Carers

- Raise the profile of young carers and their specific issues (sleep deprivation/ time constraints/ bullying), and ensure greater awareness and flexibility in schools to support young carers in managing caring alongside their education.
- Develop support groups for young carers who have a sibling with a disability/additional needs.
- Ensure a greater range and volume of young carer support - i.e. activities/skills sessions/residential.

## Areas for Action

### Carers: Health

- Develop more flexible health arrangements for carers (e.g. flexible appointments, carer health drop-in clinics, yearly health checks, etc.).
- Work to further raise the profile of carers amongst health care colleagues to ensure carers are appropriately supported.

### Work, Education and Training

- Support local employers to identify carers, understand their needs and highlight the benefit of a carer friendly workforce. In doing so, encourage employers to develop protocols for supporting carers in their workplace (e.g. flexible working).
- Improve the information provision and support to carers to get back into training/work during or after caring, including the promotion of flexible working for carers.

### Financial

- Ensure carers are supported to gain access to all of the benefits they are entitled to, to reduce carer poverty wherever possible.

### Housing

- Ensure on-going support to help carers' access good housing support and services, (including housing options, equipment and adaptation services and telecare) to support the carer and cared for to remain in their own home.

## **Carers are recognised as expert care partners and are involved in care and support planning for the cared for**

### Gaps identified during consultation

- Wider recognition is required by health and care professionals of carers as expert care partners in the condition of their cared for person.
- Greater inclusion of carers must be ensured when the cared for person's situation changes e.g. discharge from hospital, going into residential care, at key life transitions and in emergency situations.
- A simple and clear process needs to exist to ensure consent/confidentiality protocols are not a barrier to carer inclusion, i.e. for carers to easily be involved in care and support planning for the cared for.
- Increased involvement of carers is required as expert partners, particularly where there are difficult family/caring relationships.

### Ensure appropriate training/awareness raising to support the recognition of carers as expert care partners

- Ensure that 'carers as expert care partners' is included in any awareness raising or training provided on carer related topics in NEL.
- Work on promoting carers as expert care partners across all health and social care.
- Continue to support carers to assist with/deliver training to professionals and other carers so they can pass on their experience, knowledge and skills.

## **Areas for Action**

### Ensure carer involvement throughout the carer's and cared for person's care and support journey

- Ensure carers are fully involved and supported to highlight their ability and willingness to continue to provide care to the cared for person (no assumptions to be made on what they will provide).
- Ensure that confidentiality/information sharing policies do not exclude carers from relevant information pertaining to the cared for person (subject to consent).
- Ensure greater inclusion of carers when the cared for person's situation changes/ during periods of transition to ensure their voice is heard e.g. discharge from hospital, going into residential care, at key life transitions and in emergency situations.

# Carers are involved in service design, delivery and monitoring

## Gaps identified during consultation

- Carers need to be provided with the skills/tools to enable active and meaningful participation in service design, delivery and monitoring (e.g. training on how health and social care commission services).
- A range of involvement/inclusion methods is needed to ensure all carers can participate in the design/delivery and monitoring of services, such as surveys, focus groups, workshops, briefing sessions, consultation events and carer panels.
- Regular and on-going feedback is required from carers to ensure services are constantly monitored and evaluated.
- Greater inclusion of carers in contract monitoring meetings is required.
- Increased involvement of carers is required in the designing, delivery and monitoring of services for the cared for person.

### Carers' Forums

- Continue to develop carers' forums to ensure carers have an active voice locally, by supporting the forums with new membership, applications for NEL CSS funding, etc.

### Carer Led Approach

- Encourage greater involvement of carers in relevant contract monitoring (carer and cared for persons' services) to ensure quality service provision.
- Promote carer ambassadors to represent carers across the whole health and care system.
- Support the inclusion of carers within wider community agendas across NEL.
- Continue to develop and move forward with a more creative carer led approach, ensuring carers are embedded in all aspects of service design, delivery and monitoring.
- Develop a wide range of feedback options to ensure regular and on-going feedback from carers to constantly monitor and evaluate services by those who use them.
- Provision of quarterly consultation events to ensure on-going feedback from carers on carer related support and services and inclusion of carers in the wider carers' agenda.

## Areas for Action

### Training

- Develop training/support where necessary for all carers to enable carers to have active and meaningful participation and engagement in service design, delivery and monitoring. Barriers to carer participation will be mitigated as far as possible, e.g. by ensuring locations, dates, timing, language of promotion doesn't exclude carers.

### Summary

The key areas for action will be developed into a clear SMART annual action plan, which will support the realisation of the vision.