

# LUTON CARERS STRATEGY

## CARING FOR CARERS



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Luton Clinical Commissioning Group

## VOL ORG LOGOS

January 2013

## **FOREWORD** Message from Adult Social Care Portfolio Holder

Around one in five people will become carers at some point in their lives.

Hidden carers often spend more than 20 hours a week looking after loved ones.

Without help and support, they can find themselves struggling with what can be very physical and emotional demands, trying to balance work and home life, and potentially risking their own health and wellbeing as a result.

Carers give a vital contribution to their families and communities providing unpaid support for someone who is ill, frail or disabled.

Supporting carers to enable them to meet their own needs is a key focus for the council and we continue to actively support them.

We value the work of our carers, who are quite literally, indispensable.

It is important carers are aware help is out there; whether it's just having someone to talk to, guidance on benefit entitlements or simply understanding the support available.

The hard work and dedication of carers means putting their own lives on hold or missing out on things themselves because of their commitment to that person.

*Luton Borough Council and NHS Luton recognise and value the contribution made by carers. By caring for people in their own time they help people to retain their independence and to live within the community. Therefore supporting carers' well-being is in everybody's interest.*

**Councillor Mahmood Hussain (Portfolio Holder Adult Social Care)**

*Luton Borough Council and NHS Luton will work to the identified actions with the National Carers Strategy (Recognised, Valued and Supported – next steps for the carers strategy 2010). These actions will be taken over four years to support the priorities laid down nationally to ensure the best possible outcomes for carers and those they support*

Luton CCG recognises the immense work and contribution carers make to society. I am very enthusiastic that Luton CCG offers carers the support and care they need and that Luton CCG will be a key contributor to not only developing, but also implementing the Carers Strategy. We will work with our partners in the Borough council and with stake holders to ensure that all Primary care services are fully aware of the strategy and will encourage active participation.

Dr Barhey

Chair Luton CCG

## **What is the aim of this Strategy?**

The aim of the strategy is to identify what we want life to be like for carers in Luton, based on what carers told us themselves, and the priorities for how it will be achieved. The overall aim of the strategy is to ensure that carers are recognised and valued as being fundamental to strong families and stable communities and have opportunities to live healthy, fulfilling and enjoyable lives.

## **What is the scope of this Strategy?**

The strategy sets out the types of services needed by carers and how they will be provided in the future.

This strategy is concerned with direct support for carers and carers' services, and influencing all health and social care services and the wider community to understand and respond to the needs of carers. It directly addresses investment in carer's services, whilst recognising the importance of, and investment in, carer breaks provided when older and people with a disability use services such as day care, short breaks (respite), sitting services.

Our Joint Commissioning team allow the authority to put personalisation into practice by consulting and working closely with customers, carers and stakeholders. They are currently working on producing a suite of commissioning and market shaping strategies that will provide key information on the direction of the authority. The team have also worked with the Department of Health in consulting on the draft Care and Support Bill, which will put personal budgets on a statutory footing.

All strategies for 'service-user groups' (e.g. Older People, Physical Disability and Sensory Need, Learning Disability, People on the Autistic Spectrum, Mental Health, Substance Misuse) address the needs of carers. This again underlines the importance of working together across service and organisational boundaries.

We will monitor and measure the success of this strategy through an implementation plan. This will make clear who will be responsible for the work that is needed to implement the strategy and the outcomes will be tracked and reported through our Carers Partnership Board and Health & Well-Being Board.

## SECTION 1 EXECUTIVE SUMMARY

'Caring for Carers' is a joint Luton Council and NHS Luton strategy with support from a range of local organisations (including SEPT – South Essex Partnership Trust – Mental Health Trust) which will enable the vision to be achieved by setting out the types of services needed by carers and how they will be provided in the future.

The Strategy will help to ensure that carers are recognised and valued as being fundamental to strong families and stable communities and have opportunities to live healthy, fulfilling and enjoyable lives.

**'The needs of carers must, over the next ten years, be elevated to the centre of family policy and receive the recognition and status they deserve'**

**National Carers Strategy**

The future will bring many demographic challenges to society and the economy – people are living longer, more people are living with long term health conditions and we have rising expectations to keep maximum independence and control over our own lives. This will result in an increasing number of people who are and will be taking on a caring role at some point in their lives. It is predicted that by 2017 the number of older people needing care could outstrip the number of working age family members available to meet the demand.

Attitudes and expectations are changing and people will be expecting a higher degree of quality, choice and control in the way their needs can be met. Personalised solutions will be required to fit around individual and family preferences.

### **Draft Care and Support Bill – White Paper.**

The new draft Bill provides legal recognition for carers and creates a Duty for local authorities to undertake a Carers Assessment.

The Duty is not only to assess but to provide services in relation to the eligibility thresholds that will be introduced when the Draft Care and Support Bill is finalised. Carers' rights to assessment, support planning and personal budgets or direct payments will have an equal status to people with support needs.

There are several issues raised from the consultation which are being considered to be included into the Bill which all local authorities will be waiting for clarity on ie. eligibility thresholds, inclusion or exclusion of young carers. This strategy will be updated in line with the Bill and guidance.

**'Carers are the first line of prevention. Their support often stops problems from escalating to the point where more intensive packages of support become necessary. But carers need to be properly identified and supported'.**

**A Vision for Adult Social Care**

This strategy identifies four commissioning priorities based on the 2010 National Carers Strategy:

- Identifying and recognising the contribution of carers
- Enabling carers to fulfil their potential
- Personalised support for carers
- Supporting carers to be healthy

Under each priority we identify areas for development. The strategy will have an Action Plan, regularly tracked and updated to ensure we achieve the aims set within it.

The Council is facing significant budget challenges. The NHS has some protection in the Comprehensive Spending Review but there will still be changes to budgets and structures. Locally we need to ensure that we obtain the best value for money and one of the best ways is recognising carers as partners to help ensure money is spent wisely on services that meet their needs.

It is acknowledged that supporting carers is not just the job of staff working in Health and Social Care. All services, organisations and individuals can contribute by recognising the role and contribution carers make to society and by making sure they think about and include carers in ways they design and provide services or go about daily lives.

**'Big Society is also about encouraging people from all walks of life to play a more active part in society – developing a society that is more responsive and accessible to the needs of carers should be a key strand'**

**Recognised, Valued and Supported, Next Steps for the Carers Strategy**

We have made good progress with developing carers services and some of the ways carers have and continue to be involved are

- Carers Forum – feeding into the Carers Partnership Board that will feed into the Health and Wellbeing Board.
- Carers from Black, Asian and minority groups are supported to attend and/or feed into service developments in a way that meets their cultural needs.
- Chairing the Learning Disability Carers Forum – leading to membership of executive of the Learning Disability Partnership Board
- Chairing the Carers Partnership Board (carer currently being sought).
- working groups developing the autism strategy (**2011**), and the dementia strategy (**2011**).
- developing carer awareness training for staff
- Membership of project groups – i.e. learning disability respite review
- Fulfilling Lives Partnership Board for people with Autism their families and carers. Carers have been participating in developing services for people on the Autistic Spectrum.

## SECTION 2 VISION AND OUTCOMES

The Vision for Luton 2026 agreed with our partners is that 'People will be proud of Luton – a lively, hopeful, can-do town' The Council's objective is to become an excellent Council that is customer focused, delivering excellent services and contributing to the positive transformation of Luton.

The Health and Wellbeing Strategy sets out Luton's approach to improving health and wellbeing and reducing health inequalities. It provides a framework to tackle the key health issues identified in the JSNA grouped under three key outcome areas:

- Every child and young person has a healthy start in life
- Reduced health inequalities within Luton
- Healthier and more independent adults and older people

Improving the health of carers and young carers was identified as a priority in the JSNA and progress will be monitored by the Healthier and More Independent Adults Board

We want to make sure that we are supporting carers in line with the National Carers Strategy and in line with this Carers in Luton will be recognised and valued as being fundamental to strong families and stable communities and have opportunities to live healthy, fulfilling and enjoyable lives. Based on what carers have told us are the most important things, we want Luton to be a place where carers can achieve their own outcomes around **Choice and Control, Health and Wellbeing, Economic Wellbeing, Safety and Dignity, and Enjoy and Achieve**

## SECTION 3 INTRODUCTION

### Who is a carer?

A Carer is someone who spends a proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Anyone may become a carer. Carers come from all walks of life, all cultures, and can be of any age. Many feel they are doing what anyone else would do in the same situation; looking after a parent, an adult child, a friend or neighbour.

Carers are not a generic group, with common circumstances and problems. Some groups of carers are more difficult to reach, and others have particular needs, so specific strategies may be appropriate.

All partners will be encouraged to avoid stereotypes. Below is some information that we know from national research. Carers can be

- young
- parents,
- have learning difficulties
- There may be more than one carer involved with a person. Those carers may have very different needs and views. They may even be in conflict with each other
- There will often be 'mutual caring' arrangements. An elderly couple will often be carers of each other, as will an elderly parent with an adult child with a learning disability
- Sometimes people may not be keen on their carer being identified and classified as such, for various reasons and likewise carers may not be keen to be identified or classified as a carer.
- The main, or only, carer may not necessarily be the next of kin.
- The carer may or may not live in the same town as the person they provide care to.

## SECTION 4 THE BIG PICTURE

There have been many white papers, strategies, guidance and initiatives nationally to ensure that carers are recognised, valued and supported in their caring role. These are being used to underpin the work undertaken by all partners in the Strategy

Full details and links to websites can be found in Appendix 4.

### National Carer Profile

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The number of people providing unpaid care for disabled, sick or elderly relatives and loved ones has risen substantially in the last decade.

Census data released December 2012 reveals that the number of carers increased from 5.2 million to 5.8 million in England and Wales between 2001 and 2011. The greatest rise has been among those providing over 20 hours care – the point at which caring starts to significantly impact on the health and wellbeing of the carer, and their ability to hold down paid employment alongside their caring responsibilities.

Across England and Wales there are now a staggering 2.1 million people providing over 20 hours a week - a rise of almost half a million people in the last 10 years. Those providing the most number of hours of care – over 50 hours a week and very often caring round-the-clock - has in itself risen by 270,000 and is up from 1,088,000 to 1,360,000.

The 2011 Census reveals Wales still has the highest percentage of residents who are providing care compared with any other region in England

The number of people aged over 85 in England is set to double by 2025 and the number of carers is set to soar from 6 million to 9 million by 2037. Three in five people will be carers at some point in their lives.

### Eastern Region Carers Profile

Carers in the Region, A Profile of East England<sup>1</sup>, published in November 2009 by the University of Leeds, aimed to provide better information about carers at a regional level. The profile indicated over half a million carers in the region and:

- Over 4,500 people aged 85+ undertaking a caring role
- At least 17,000 young people aged under 20 who are caring for someone and 1200 aged between 5 and 9 years old.
- Over 96,000 people caring for 50+ hours a week
- Over 51,000 carers who considered themselves to be in poor health
- Over 270,000 people trying to combine work and a caring role
- 72% of carers worse off financially as a result of caring
- The number of carers in the region is expected to increase by over 119,000 or 18% compared with 15% in England between 2008 and 2030

<sup>1</sup> Carers in the Region, A profile of Carers Strategy V17 inc feedback changes

This information is the latest collated information from the Eastern Region Carers Lead (enableeast) and will be updated in due course.

## **Carers Profile (Local)**

The 2011 Census identified 18,256 carers in Luton, of whom 4886 are providing 50+ hours of unpaid care each week. This is an increase of 13% on the number of carers identified in the 2001 Census.

Consistent with national trends we expect the number of carers in the town to increase. This will be at least in line with growth in the general population<sup>2</sup>, but in reality the picture is likely to be much more dramatic, with the numbers of older and people with a disability as a percentage of the population increasing and therefore the percentage of carers in the town increasing too.

### **Young Carers**

## **Background and Demographic Information/Indicative Volume**

According to the Office for National Statistics (ONS), the population of Luton was 186,800 in 2006. Research undertaken by the Council suggests that this is an underestimate of the population and a figure of 202,500 is more realistic. With an area of 4336 hectares, these population figures translate into a population density on either 43.1 persons per hectare or 46.7 persons per hectare respectively.

The ONS Mid-year population estimates indicate that the age structure of Luton's population differs from that of Great Britain's population as a whole. Luton has a younger population than that of Great Britain and the eastern region. The "Over 65" age group represents 12% of the Luton population compared with 16% nationally and regionally.

The Borough is ethnically diverse, with approximately 35% of the population being of Black and Minority Ethnic origin, with significant Pakistani, Bangladeshi, Indian and African Caribbean communities. In recent years the diversity of the population has increased with foreign students coming to the University of Bedfordshire and the arrival of citizens from other European Union countries, notably, Poland and other Eastern European countries. Twenty per cent of the population was born outside the UK. The most frequently used languages in Luton other than English are Bengali/Sylheti, Urdu/Pahari, Punjabi, Gujarati and Polish.

According to the 2001 Census there were 16,000 Carers in Luton. The General Lifestyle Survey states that Carers are most commonly aged between 45-64 years of age and a study conducted by Maher and Green (2002) indicates that nationally half of all Carers are caring for someone aged over 75 years of age. We also know from studies conducted by the University of York (2004) that a significant number of people each year are new to caring and that the health of Carers can be affected by the caring role.

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<sup>2</sup> Luton Joint Strategic Needs Assessment 2011  
Carers Strategy V17 inc feedback changes

Further information about Luton's demographic profile and can be found in the Joint Strategic Needs Assessment, this can be located on the Council's Website; or using the following link:  
<http://www.lutonpct.nhs.uk/downloads/content/Final%20JSNA%202011.pdf>

This increase is supported by local information such as:

- There will be approximately 35,500 people over the age of 65 living in Luton by 2030 an increase of 27%
- The number of working age people with dementia in Luton is predicted to rise from 41 in 2010 to 56 in 2030 .
- It is predicted that there will be 20% more people aged over 65 with dementia in Luton by 2020 a rise from 8.9% (2010–14) Luton has higher than average rate of illness and disability among children<sup>3</sup>, which will lead to more carers of children with disabilities, and caring relationships which continue as children reach adulthood. These carers are very often the parents but may include grandparents, sibling young carers, and other family, neighbours and friends

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<sup>3</sup> The born in Luton study  
Carers Strategy V17 inc feedback changes

## SECTION 5 WHAT IS ON OFFER FOR CARERS IN LUTON?

Services to support carers have historically been funded either by specific grants paid by the government to the local authority (e.g. Carers Grant), or as part of wider support packages for disabled children, disabled adults and older people (e.g. Continuing Healthcare, Aiming High for Disabled Children) and mainstream services such as home care, day care, short break in care homes, NHS commission. We currently provide the following statutory services

### Current services commissioned or run by Luton Borough Council directly

#### Carer's Assessment Worker

Luton has a Carers' Assessment Worker based in the customer service centre, which enables their needs to be identified and the support provided by the Council or signposted to organisations that can provide services or support.

#### Specialist Carers Support

A Carers Social Worker is employed within **SEPT** (mental health service) in Luton to assist those caring for people with Mental Health illness.

#### Carers Emergency Plans

Currently Carers Emergency Plans are undertaken by a worker who is employed by the Council. The Plans are carried out to help the Carer to think about and where necessary identify what support they may need in the event of an emergency occurring. In the longer term this will be embedded in the Carers Assessment process and voluntary sector organisations will work with carers at the outset to engage them in thinking about emergency planning.

#### Services that provide a break for carers

The councils 'Shared Lives', and 'Sitting Services' and short breaks (respite) for older and people with a disability provide a break for carers. Further information can be found at [www.luton.gov.uk/carers](http://www.luton.gov.uk/carers)

#### Direct Payments for Carers

The Carers Direct Payments Scheme provide one-off payments to carers to promote their own health and well-being, pay towards a short break for them or purchase equipment that will ease their caring role.

#### Support for Young Carers **Caroline Thomas pending**

Family Action provide a Young Carers service which included individual work with young carers, time-limited groups and activities, signposting young carers to relevant services and supporting young carers through advocacy.

### **Meet & Greet service for Carers of people with Dementia**

A service provided to provide information and support to carers following Dementia/Alzheimer's diagnosis of the person they care for. Partnership working between Luton Borough Council, SEPT(Mental Health Trust) and Alzheimer's Society

In addition there are many voluntary and community sector organisations that provide a range of services for older and people with a disability, which provide support to carers. Many of these organisations are small local organisations and they receive their funding from a variety of sources e.g. Health and Wellbeing Luncheon clubs, Headway, Luton Mind.

## **Where the funding comes from**

### **Carers Grant**

In the past councils used to receive a specific grant from central government that had to be spent on services for carers. This has now ended and the money has been included within the overall funding allocated to Councils. However Luton Borough Council continues to spend the same amount on services for carers. In 2012/13 Luton Borough Council will spend around xx million funding a range of Community and Voluntary Sector schemes and services that support carers young carers, carers of working age adults and carers of older people.

For the NHS local Primary Care Trusts have also been allocated money for carers over the past few years. However this money has not been ring fenced and so many PCTs (including Luton) have struggled to allocate this money to services for carers. However for 2013/14 onwards Luton CCG have been able to allocate £50,000 to develop a carers pooled budget in partnership with LBC and to improving information and advice available at GP surgeries.

## **Local Progress and Developments**

### **Partnership Arrangements for carers**

A reformed multi-agency Carers Partnership Board which met for the first time in February 2012, and a Carers Forum to feed into the Partnership Board. These arrangements will mean that carers will continue to be contributing to service planning and influencing service design. There will be early engagement with providers in developing strategies and testing out new types of working.

It is envisaged that this will lead to better quality services that in turn lead to outcomes that are important to carers as well as individual and policy decisions being more carer focused. There will also be greater awareness of the needs and aspirations of carers and a greater understanding across all services and sectors of why and how services need to change.

A Professionals Bulletin is being introduced to raise carer awareness and to provide up-to date information for staff in both the statutory and voluntary sectors about carer issues

### **Carers Health Checks**

We are in discussion with Luton CCG with an aim to work with a number of GP practices in the town to provide annual health checks for carers. The health check provides an opportunity for

carers to have a more systematic and in-depth discussion about their health and social care needs in primary care.

### **Carers Direct Payment Scheme**

In 2011/12, 504 carers received a Carers Direct Payment of up to £200. Many carers have written stating their satisfaction and enjoyment. The letters reflect the general gratitude of carers that someone is putting them first and gives them a boost to continue caring.

- "It felt so special to think that someone had thought about me"
- "It was a very welcome break away from home and a nice change"
- "I definitely benefited from the reflexology which left me feeling relaxed"
- "Having just a couple of hours a week to myself is priceless and I believe it gives me the energy to continue caring."

While recognising the value of providing one-off payments to carers, we also recognise that demand can sometimes be higher than the budget. They are linked to Carers Assessment and an identified need for a break. We are looking at ways to administer the Carers Direct Payment in a more cost effective way.

### **Carers from Minority Ethnic communities**

We provide funding to groups to enable them to meet the diverse needs within the community. This allows support to be provided in a culturally appropriate way i.e. meeting language need, values and use ways to encourage participation. i.e. a specific mental health carers support commenced following an identified gap in service needs.

### **Carers and Dementia**

Luton's Dementia Strategy was completed & consulted in 2011. Work has commenced on the action plans. The Work Streams responsible for delivering and monitoring the Luton Dementia Strategy identified the following priorities.

- Early Intervention and Diagnosis
- Quality of Care
- Workforce Training and Development
- End of Life
  
- Community Development Workers and Prevention Project Workers who work specifically with minority groups are extending their remit to include Polish, Bosnian, Romanian and other communities.

### **Carers of Adults with a Learning Disability.**

Luton has a Learning Disability Parent and Carers Forum which is chaired by a family carer. Meetings are held on a cycle in line with the Adult Learning Disability Partnership Board and information is exchanged on issues relating to main themes of Learning Disability, Health, Housing, Day Opportunitites between the forums and subgroups.

The group has its own terms of reference and the group and individual members are regularly involved in consultations to shape services in Luton.

### **Carers as Partners in Hospital Discharge**

We have started to look at how we can best support carers as partners in hospital discharge. Staff from Luton & Dunstable Hospital NHS Foundation Trust and Luton Borough Council are involved in writing an action plan that will set out the things that need to happen and who is responsible.

Key issues from the work have been carer identification and recognition, information for carers in the hospital setting and emotional and practical support.

**Carers and End of Life Care** Most people would prefer to die at home, but it is more likely that people die in a hospital or care home. Enabling more people to experience good end of life care in the place of their choice, will require improvements in support and training for carers.

We are reviewing in association with other agencies how we can best support carers who are caring for someone who is dying.

### **Post Caring**

**Paragraph to be inserted - Diane**

### **Carers Rights Day and Carers Week**

We will continue to ensure that we link with national publicity programmes to ensure that carers have the opportunity to receive information and advice about what is available to support them in their caring role.

In the past we have held successful events for carers on Carers Rights Day and Carers Week. These included SOS Bus in St George square, Picnic in the Park, Carers Question Time. The events, which have been run in partnership with NHS Luton, SEPT, Luton Culture and other Voluntary Sector organisations, have attracted a large number of carers.

Quotes from Carers following Carers Week Events over previous 2 years

- "A very enjoyable and relaxing day"
- "Its been absolutely fantastic, really enjoyed myself, lots of good information and good food too"
- "Very helpful-I've just moved to the area and found lots of useful information"
- "I am happy and de-stressed. I have thoroughly enjoyed it"

## **Improving Carers Assessments**

Often, both staff and carers are not aware of the purpose or potential benefit of Carer's Assessment, or what might be available for carers as an outcome of their assessment. In 2011 we updated our Carers Assessment to incorporate sections and questions that will assist carers to think about and for staff to be mindful about issues that affect carers. With this in mind, work has started to look at how we can integrate the carer's assessment into or alongside the the Self Assessment which will be introduced within Adult Social Care.(by 2014)

Integrating the carers assessment and the Self Directed Questionnaire would mean that carers views are taken into account when planning the support for the cared-for-person, and the carers own needs are being assessed and a carer support plan completed.

This strategy also suggests that we consider the options for developing 'trusted assessors' is updated. This will ensure that carers are recognised as partners in care. The training includes the legal framework, working with carers as expert partners, carers needs and what resources there are to support carers. It could also lead to Carers Health Checks being incorporated into the Carers Assessment if they were carried out in the Doctor's Surgery.

## **Carers Activity Projects**

Community Groups that provide support for minority ethnic groups provide a range of activities for carers. Some of the activities help carers to learn new skills or a hobby. There are also opportunities for carers to get peer support & information & advice in a culturally appropriate setting.

## **Changing Lives Programme**

In 2011 we commissioned 'Moving Forward' supportive carers workshops. The workshops support family carers of somebody with a learning disability who may be thinking about the future and the changes involved when the person they care for moves away from the family home. The workshops looked at the emotional issues of 'letting go' as well as the practical subjects of types of accommodation and support available.

Luton jointly funded courses with Central Bedfordshire Council to make the delivery cost effective. We are waiting for the evaluation to establish any future commissioning.

## **Carers Support Service**

We have consulted with carers about the type of Service they would like to see in Luton to support them. We are currently looking at a tendering exercise to invite voluntary organisations to provide support to carers along the four priorities of the 2010 National Carers Strategy.

## SECTION 6 OPPORTUNITIES AND CHALLENGES

### Funding

The Carers grant is now part of overall revenue funding and whilst consistent policy messages to prioritise carers and preventative support, this must be seen in the context of cuts to local government expenditure and increasing populations of vulnerable people in Luton. It will provide a challenge for the Council and local NHS Luton to ensure that the value of support to carers is recognised, receives equal consideration alongside other service priorities, and that we commission jointly. This gives an opportunity for joint working across partnerships to ensure we make best use of resources as well as achieving the best possible outcomes for carers.

### Equality & Diversity

There are some groups of carers who experience multiple disadvantages and isolation, for example carers who are disabled, black and minority ethnic carers, gay, bisexual and transgender and carers of some disability groups have found it difficult to access services ie Autism. It follows that these groups of carers may be least likely to access appropriate information and support.

This strategy recognises the full diversity of carers, and aims to ensure that services for **all carers** are improved and are fully accessible. This includes taking due regard of equality strands but recognises that diversity of carers covers more than this, e.g. education and employment, health of carers, diversity of the people cared-for, income and finance and the impact of caring for more than 50 hours per week.

The 2010 Equality Act<sup>4</sup> includes measures regarding discrimination by association in relation to disabled or older people. The act has the potential to reduce the strain on some carers, particularly when fitting caring responsibilities around employment, as they will have greater protection from discrimination as a result of their caring responsibilities.

### National Population Challenges

Changes in population is one of the greatest challenges facing our society and our economy. Carers UK 'Tipping Point for Care'<sup>5</sup> report suggests that by 2017 we will reach the 'tipping point' for care when the numbers of older people needing care will outstrip the numbers of working age family members currently available to meet that demand. This is due to a range of demographic driver:

- An ageing population and more people living longer with disability as a result of advances in medical technology
- An ageing workforce, with fewer young people entering the job market and later retirement ages
- More people needing to balance work and care longer

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<sup>4</sup> 'website'

<sup>5</sup> Tipping Point for Care, time for a new social contract; Carers UK; February 2010  
Carers Strategy V17 inc feedback changes

- The number of working age people with disability is on the increase
- Increasing numbers of people and over the age of 65 with dementia

### **Expectations from Carers**

Attitudes and expectations are also changing and quite rightly carers should expect high quality services that they have more control over. The expectations of carers in the next 20 years are likely to be different to carers now.

People are much more socially mobile than before and have generally experienced a wider exposure to different goods, services and life experiences than ever before. People now, and in the future, will expect more from their local authority and care providers in terms of the range and quality of services on offer.

### **Developing the market for new and relevant services**

The Council, as the lead-commissioning organisation for carers, has a key role to play in shaping the health and social care market, to make sure that the right amount and range of services are available for carers and the people they care for. It is essential that strong partnerships are actively developed with current and potential providers of all sizes and in all sectors; to ensure that excellent services are available to achieve good outcomes for carers.

The Department of Health is funding the [Developing Care Markets for Quality and Choice programme](#) which will support local authorities to develop market position statements, setting out how they will commission local services in the future and develop good relationships with their range of local providers. The DoH will be visiting Luton Adult Social Care in April 2013 to work [with us](#) to produce a market position statement.

Developing the Market will mean that Luton becomes a better place for carers to live and that commissioners use influence creatively to ensure that carers become less dependant on services by enabling a range of community facilities to be in place to help carers quickly and effectively when necessary. This includes a potentially wide-ranging role for the Carers Partnership Board, through the strategy action plan to ensure carers are part of mainstream social, community and economic life and can access universal services.

It is important that health and social care services, schools, voluntary organisations, faith and community organisations, employers and the wider community recognise and act to secure the benefits that can be gained by supporting carers of all ages. All these organisations, whether local or national, have a crucial role in helping people to identify themselves as having a caring role and signposting them to the relevant sources of information and advice. This will help to ensure that they are not isolated or financially disadvantaged and that their health is not adversely affected as a result of their caring role.

## Appendix 1

### Background information

Many of us will be carers at some stage in our lives. It is a role that can come unexpectedly out of a crisis; it is a role that can creep up on you. Being a carer provokes a complex mix of emotions. It can be both rewarding and frustrating. It can be costly in life chances, financial security and health.

By 2037 it is estimated that there will be up to 3.4 million carers in England. The 2001 census advised that there were over 16,000 carers in Luton and we await the results of the 2011 census for up to date figures.

Luton Borough Council and NHS Luton recognise and value the contribution made by carers. By caring for people in their own time they help people to retain their independence and to live within the community. Therefore supporting carers' well-being is in everybody's interest.

Luton Borough Council and NHS Luton will work to the identified actions with the National Carers Strategy (Recognised, Valued and Supported – next steps for the carers strategy 2010). These actions will be taken over four years to support the priorities laid down nationally to ensure the best possible outcomes for carers and those they support, these include:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well.

The above are recognised priorities to bear in mind when planning for carer support but it must be remembered that every carer is unique as is the individual caring role and there is an overriding need to personalise support to fit around particular preferences.

**Carers** often provide help and support that if anything happened to them would have to be provided by statutory services either in full or in part.

From the hours that carers say are spent caring, and the average hourly rate for care provision, it is estimated that nationally carers contribute work to the value of £119 billion per year<sup>6</sup>. This is the estimated cost of running the whole Health Service.

For this reason alone it is enough to support them. However carers must also be recognised as an 'at risk' group in health and social care terms because they are at risk of

- physical ailments such as back strain caused by lifting
- stress-related conditions

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<sup>6</sup> Valuing Carers – Calculating the value of unpaid care, Carers UK and University of Leeds 2007  
Carers Strategy V17 inc feedback changes

- become socially isolated
- falling into financial hardship, either through loss of earnings or caring related costs
- not getting enough sleep or rest
- Mental health conditions such as anxiety or depression

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### Recognised Outcomes for Carers

#### Choice and Control

- Carers are involved in planning, commissioning decisions and service design.
- Carers are involved in the training of health and social care staff
- Carers have relevant and timely information and advice that helps them to care safely and sustain their caring role and to pursue their own life choices
- Carers have their own needs assessed and are supported to plan for their own lives including planning for the future and for emergencies
- Carers have Direct Payments<sup>7</sup> from the Council to design their own break
- Carers have appropriate support when involved in planning and managing individual budgets/direct payments for the cared-for person.

#### Health and Well Being

- Carers are well informed about and use the health and well being services that they need themselves to enjoy good physical and mental health
- Carers have opportunities to have a break from caring
- Carers have good emotional support and feel less stressed about caring, and less isolated
- Carers are enabled to maintain better relationships and provide better support for the person cared-for

#### Economic Well-being

- Carers are well informed about benefits and financial choices
- Carers are supported to maximise their income, including staying in work or returning to work

#### Safety and Dignity

- Carers identify themselves as carers at an early stage
- The contribution carers make is valued by all services
- Carers are valued as care partners and are involved in care planning eg hospital discharge, end of life care and individual care packages
- Carers are supported and trained to be skilled in the caring role

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<sup>7</sup> Carers Direct Payment is the Council's term to describe a sum of money allocated to meet carers assessed needs to give a sum of money to purchase goods and services to give them a break.

## **Enjoy and Achieve**

- Carers are able to balance their caring role with paid work, education and training.
- Carers are able to take part in activities with other carers, to access community services (ie leisure) and /or to volunteer
- Carers who are children and young people are protected from inappropriate caring and have the support they need to learn, develop and thrive.

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### What Carers say

There have been a number of surveys and other opportunities for carers to share their experiences and aspirations in recent years. The following views, expressed by carers in Luton are taken from:

- National Carers Strategy Refresh, Call for Evidence (September 2010)
- Carers Experience Survey (November 2009)
- Dementia Workshop (2011)
- Carers Consultation (September 2011)
- Learning Disabilities Respite Review (January 2012)
- Learning Disabilities Day Services Review (September 2012)

In summary carers tell us they want:

- Better recognition of the role and contribution they make
- Up to date, relevant and accessible information
- To be included in care planning and have their own needs assessed
- To be involved in shaping future service developments
- Access to and support to manage personal budgets and direct payments
- Advice training to support them in their caring role
- To be involved in training of health and social care staff
- To be able to plan ahead and plan for emergencies
- To be able to have breaks and time where they can relax
- High quality emotional support – someone who will listen to them
- Health checks and to be able to use health and wellbeing services
- To be able to continue to work or get help to find work
- Quality services for the person they care for that they can trust, so they can work, have a break or do something themselves

## Appendix 4

### Key Documents for reference

Carers at the heart of 21<sup>st</sup> – century families and communities; HM Government, June 2008

Recognised, valued and supported: Next steps for the Carers Strategy; HM Government, November 2010

A vision for Adult Social Care: Capable Communities and Active Citizens; Department of Health, November 2010

Equity and Excellence: Liberating the NHS; Department of Health, July 2010

The Operating Framework for the NHS in England 2011/12; Department of Health; December 2010

Carers and personalisation: improving outcomes; Department of Health, November 2010

Tipping Point for Care; time for a new social contract; Carers UK, February 2010

Commissioning Better Outcomes for Carers and Knowing of you have; Princess Royal Trust for Carers and ADASS, May 2010

Supporting Carers – Early interventions and Better Outcomes; Princess Royal Trust for Carers and ADASS, May 2010

Commissioning for Carers; Princess Royal Trust Carers et al, May 2009

Putting People First without Putting Carers Second; Princess Royal Trust for Carers and Crossroads, May 2008

Carers as Partners in Hospital Discharge; ADASS, 2010

Carers in the Region, A Profile of Luton; University of Leeds, November 2009

Draft Care and Support Bill

Welfare Reform 2013

Fulfilling and rewarding lives: the strategy for adults with autism in England March 2010

Living well with dementia: A national dementia strategy – 2011

Joint Commissioning Strategy - People with Dementia – Luton - 2010-2015

Joint Commissioning Strategy Adults with Autism in Luton - 2011-2016

Fulfilling Lives Partnership (developing services for people with Autism).

### What is a Carers Assessment?

A Carers Assessment is an opportunity for carers to discuss with the Social Services Department what help and support they need with their caring role.

A Carer can have an assessment if

- They are providing regular and substantial care to someone who has needs that meet the criteria for Social Care Support.
- The person you're looking after is being discharged from hospital.
- You are looking after someone with mental health problems who is on the Care Programme Approach
- You are a parent carer of a disabled child under 18. In this case, you have a right to a separate assessment of your own if the assessment for the child under the Children Act does not fully take account of your needs. (currently pending clarification in the new Care and Support Bill after consultation as it currently only supports adult carers of adults).

The Carers Assessment is not a test but an opportunity to have a discussion about any help that would help them to maintain their own health and balance caring with other aspects of their life such as work and family. The information given through the Carers Assessment will enable the Social Services Department to decide what help to provide.

How can carers get a Carers Assessment?

If the person being cared for does not receive services from Social Services carers can contact us and request a carer's assessment.

If social services are providing services to the person being looking after then carers will be offered an assessment when the person is assessed for services or when the person's care is reviewed (usually annually).

If social services are providing services to the person being looking after but there are no plans to assess them or reassess them, carers can still ask for their own carer's assessment.

If the person you're looking after is being discharged from hospital, you will be offered your own assessment as part of discussions about the plans for them leaving hospital.

### What happens at and after an assessment?

During the Carers Assessment, social services will consider whether the carer's role is sustainable and what might be offered to support them. Prior to and during the Carers Assessment carers should give consideration to

- What choices they want to make about caring. They should be free to choose whether or not you want to be a carer.
- Whether there is anything about being a carer that presents problems for their health and safety.
- Whether being a carer disrupts other commitments they have in their life, including paid work or relationships with other people.

- Account has to be taken of carer's wishes as far as employment, training and leisure are concerned.

## Appendix 6

### What is the Carers Partnership Board?

Is a regular meeting to ensure that needs of carers are represented to the Council and NHS Luton

To ensure that the carers and organisations that represent carers are fully engaged in the planning and development of services

To ensure that relevant statutory departments maintain regular contact with carers and organisations that represent carers and that there is good networking and communication across all stakeholders.

The Purpose of the group is

- To ensure that the views and needs of carers are voiced, represented and forwarded to the Health and Well Being Board, Commissioning Team and other bodies
- To enable discussion, consultation and networking with carers and organisations that represent carers in the development of strategies and new services for carers and vulnerable adults (adults at risk)
- To keep carers and organisations that work with carers informed of changes of policy and local developments which are likely to impact upon carers

### What is the Carers Forum?

### What is the Learning Disability Parent and Carers Forum?

The Parents and Carers Forum gives parents and carers a voice when services for people with learning disabilities in Luton are being considered.

The forum is open to all parents and carers of adults with learning disabilities.

Meetings are organised and facilitated by Luton Borough Council.

Guests are invited to the forum at the request of group members or partnership board representatives to discuss relevant issues.

Those attending forum meetings are encouraged to contribute their views and thoughts on the issues under discussion

## Appendix 7

### What is a Carers Emergency Plan?

A Carers Emergency Plan is drawn up for a carer providing 'regular and substantial care' and is available regardless of whether the cared for person receives any statutory services or not. It can be seen as a preventative or planning for an emergency tool.

A Carers Emergency Plan helps prompt carers to clarify their wishes about what might happen in their absence. This may involve discussion and negotiation with family and friends, or thinking about what a package of care will be required in the event of an emergency arising. The duration of the Carers Emergency Contingency Plan will normally be limited to 48hrs (up to 72hrs over a weekend/Bank holiday (if it's an extended Bank Holiday this will be covered), this period could cover the whole short period of emergency or provide a valuable window of time within which longer term arrangements may be made, where they are necessary.

An emergency is an unplanned or unforeseen event that prevents a carer from carrying out their normal caring role that in turn puts the cared for person at risk. This could include the following:

- Carer's admission to hospital or other health needs which preclude him or her from continuing to provide care e.g. emergency operation, broken limb, severe flu.
- Family emergency such as a close relative being taken ill and requiring help/attention.
- Real risk to the carer's employment on a particular occasion
- Funeral of a close friend or relative

This service **CANNOT** be used for the following:-

- A carer is finding it difficult to cope any longer
- To replace existing respite care arrangements
- To organise long-term care arrangements
- When there is an emergency with the person being cared for.

### What is a Carers Direct Payment?

A Carers Direct payment can be awarded to a carer following a Carers Assessment or Carers Review to identify support needs.

Examples of support that might be given include:

- Equipment like a washing machine or tumble dryer.
- A computer or internet connection
- A holiday or short break away for the carer
- A family holiday
- Membership of a club, association or gym or holistic therapies
- Transport costs
- Course /tuition fees

Payments cannot be used for simple income replacement. Direct Payments cannot, for example, be for electricity or gas bills, food shopping or general household goods. Payments cannot be used to pay for services for the person being cared for i.e. respite care.

## **ACTION PLAN - Working together commissioning principles.**

People who need help and use services should not be able to recognise the divisions between health, social care and support services and we should not allow organisational boundaries to get in the way of delivering excellent services. Commissioners will work with providers across voluntary, private and statutory sectors to help shape the market to deliver the personalised support that carers need.

To achieve this, the following principles will guide how the Council and NHS commission services for carers:

- Carers will be supported by a variety of methods that value their role.
- We see our role as 'place-shaping', working creatively with citizens, community groups and service providers to improve the experience of living in Luton.
- We will ensure that people have real, increasing choice and control over how to use individual budgets for social care and individual health budgets, including people who self-fund for social care; this includes good information and support, assuring quality of services and the safeguarding of vulnerable people.
- Services will be commissioned by the Joint Commissioning Team across Adult Social Care and NHS Luton. We will use pooled budgets and align all commissioning activity to ensure a joined up approach and to prevent gaps developing across the health and social care system.
- Where joint commissioning is not appropriate (e.g. NHS commissioning of hospital services), commissioning will still be undertaken in partnership to ensure a fair approach
- We will ensure that services are effective and efficient, making the best use of the local populations, as described in the Joint Strategic Needs Assessment.
- We will commission for good health and well-being, investing in prevention, independence and to reduce health inequalities

The Key priority areas for the Action plan and descriptions of what services might be developed and suggested outcomes are set out on the next 4 pages

### **Priority Area 1: Identifying and recognising the contribution of carers**

We want to support carers to identify themselves as carers at an early stage, to recognise the value of the contribution carers make to society and ensure that carers are involved from the outset, both designing local care provision and in planning individual care packages.

#### **Areas for development**

- Carers partnership arrangements, making sure we recognise the expertise of, and work in genuine partnership with carers at all levels of service design and delivery and including those carers who are often overlooked
- A carers Bulletin for Professionals and a network of Carer Champions to help health and social carer services, schools, voluntary organisations, faith and community organisations and employers to be aware of and act to support carers of all ages
- An annual carers event and supporting organisations and carers throughout Luton to be involved in Carers Week and Carers Right Day
- Workforce development including options for carers awareness e-learning packages and carer involvement in training health and social care staff
- Training for carers to support their involvement and participation in designing local care provision and planning individual care packages

#### **What this means for carers (Outcomes for Carers)**

- Carers identify themselves (and are helped to identify themselves) as carers at an early stage
- Carers have relevant and timely information and advice that helps them to care safely and sustain their caring role and to pursue their own life choices
- Carers are involved in planning, commissioning decisions and service design
- Carers are involved in the training of health and social care staff
- The contribution carers make is valued by all services
- Carers are valued as care-partners and involved in care planning, e.g. hospital discharge, end of life care and individual care packages
- Carers are supported and trained to be skilled in the caring role

## **Priority 2: Enabling carers to fulfil their potential**

We want to make sure that young carers and adult carers are supported to pursue their education, training, work and volunteering aspirations, to fulfil their potential and to protect their own and their families current and future financial position.

### **Area for development**

- Implement the Working Together to Support Young Carers protocol
- Support carers back into work or to maximise their income by joint working with partners including Job Centre Plus and the Pensions Agency to ensure that they are reaching carers as well as identifying new or existing services
- Stimulate and shape the social care market to provide reliable and affordable replacement care to enable carers to find or continue to work
- Effective 'carer-proof' policies are in place within the Council and NHS to ensure they are leading by example in employing and supporting carers

### **What this means for carers (Outcomes for Carers)**

- Carers who are children and young people are protected from inappropriate caring and have the support they need to learn, develop and thrive
- Carers are able to balance their caring role with paid work, education and training
- Carers are able to take part in activities with other carers, to access community service (e.g. leisure) and/or to volunteer
- Carers are well informed about benefits and financial choices
- Carers are supported to maximise their income, including staying in work or returning to work

### **Priority 3: Personalised support for carers**

We want carers to have their own needs considered, where possible alongside the person they care for, to have access to services tailored to their own needs, for example advice and information, and have access to individual budgets and personal health budgets so they are able to design and direct their own support

#### **Areas for development**

- A redesigned carers assessment with options for how best to integrate it with the Self Directed Questionnaire
- An 'overview' carer assessment and arrangements for 'Trusted Assessors' across partners organisations
- Consider the options for a friendly and simple approach to Direct Payments for carers who are eligible so carer can design and direct their own support
- Shaping the market, to improve the 'offer' for carers; we wish to see a range of support options and opportunities, both generic and specialist, linking carers to communities, volunteering opportunities for carers
- Targeted interventions e.g. the use of tele-health and tele-care

#### **What this means for carers (Outcomes for Carers)**

- Carers have their own needs assessed and are supported to plan for their own lives including planning for the future and for emergencies
- Carers have relevant and timely information and advice that helps them to care safely and sustain their caring role and to pursue their own life choices
- Carers have access to individual budgets and are designing and directing their own support
- Carers have appropriate support when involved in planning and managing individuals accounts for the cared-for person

#### **Priority 4: Supporting carers to be healthy**

We want to make sure that carers can look after their well-being, and avoid neglecting or damaging their own health because they are caring for someone else or following bereavement.

##### **Areas for development**

- Dedicated Carers Support Worker in Primary Care settings, e.g. GP Practices, consistent across the town and provided in the most cost effective way
- Dedicated Carer Support Worker capacity in hospital and hospice settings to support carers in safe and timely discharge and end of life care
- Carer health checks including reaching out to carers who are often overlooked
- A range of jointly commissioned services that provided carers breaks
- A range of training opportunities for carers to ensure that carers can care safely and sustainably
- Bereavement support, including 'aftercare' when the cared-for person has received end-of-life care

##### **What this means for carers (Outcomes for Carers)**

- Carers are well informed about and use health and wellbeing services that they need themselves to enjoy good physical and mental health
- Carers have opportunities to have a break from caring
- Carers have good emotional support and feel less stressed about caring, and less isolated
- Carers are enabled to maintain better relationships and provide better support for the person cared-for

**Back page – either at the end of the Strategy or the end of the Action Plan if the Action Plan is to form part of the Strategy Document.**

This document is produced by Luton Borough Council.

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