

DAA

Luton Dementia Action Alliance



**Luton Dementia Guide
2015**



Foreword

When I first got involved with the co-production project, I said that what was needed in the town was a single booklet which people would be given when they are diagnosed, containing all the info they need. I think you have ticked all the boxes so to speak. I think there are too many leaflets and booklets around which carers like me don't have time to read! I am therefore very pleased that one is being produced.

Jeff Solomons

Carer

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Someday those who care for a person with Alzheimer's may be faced with what appears to be an insoluble problem. Caregivers may try anything they have been taught but nothing works. So, they touch the arm of the person with Alzheimer's and speak softly and gently. Because of the patient's apparent distress, the caregiver may hug the person with Alzheimer's or give a kiss and tell the person that he or she is loved. One day, if the caregiver is lucky, a revelation occurs. That person learns that the last thing we ever lose is love. Our memories may be gone. Intellect and logic may have diminished. We may have forgotten your name and where we are, or what we are doing. But we remember love.

TIM BRENNAN

From 'Perspectives: A Newsletter for Individuals with Alzheimer's' ed. Lisa Snyder 4 (2) 7 (1999) Available by email – contact: lsnyder@ucsd.edu

Our Top Tips for people diagnosed with dementia are:

- It's okay to be angry and upset! The quicker you can move past this, the more time you have to do the things you want to.
- Involve your family and friends – tell them what you would like, what's important to you and how you want to live your life.
- Get organised: attend to your legal affairs, including nominating someone you want to handle your financial affairs as soon as possible.
- Get as much advice from trusted sources as you can and spend time thinking through your options
- Enjoy life, make a bucket list with those you love and do the things you want to do; don't needlessly put it off!

Our Top Tips for carers are:

- Get good at recording; keep a diary or notebook and record everything! Signs, symptoms, likes, dislikes, what doctors said, what social workers said, names of people involved etc. There is a lot of admin in caring!
- Get organised: have a plan for emergencies, make a will and legal arrangements, claim benefits, think ahead!
- Get help and advice: it's complicated so turn to trusted sources such as voluntary organisations working locally
- Accept help: whether it's from family, friends or organisations involved in your loved one's health care.
- Look after yourself and don't get too run down!

SAFEGUARDING

Everybody who works with you and the person you care for should treat you respectfully, listen to what you both have to say and never force either of you to do anything you are not comfortable doing or which impedes on your dignity. If you feel either of you are being put into this position you should discuss it with those involved in your care or, if you feel strongly, make a formal complaint. The council, health services and all providers who hold contracts with these bodies are obliged to have formal complaints procedures.

Sometimes you may feel that what is happening to you, or the person you care for, is abuse. This may be financial impropriety, physical, emotional or sexual abuse or neglect of a person's care needs. Luton Borough Council's Safeguarding team can discuss these concerns with you and, in partnership with the police, investigate these matters. They can then put in place measures to stop the abuse and safeguard you or the person you care for thereby protecting you from future harm.

If you suspect abuse is occurring or have any concerns please contact Adult Social Care on 01582 547730, 01582 547563 or e-mail: adultsafeguarding@luton.gov.uk



“He was forgetful but he covered it really well, looking back I think it must have been going on for a few years” Sadie, 71

CARING FOR SOMEONE WITH DEMENTIA



**“It’s not like getting a job where one day you suddenly start caring... for me it was very gradual. I was having to do more and more to support Mum and it was only when I fell ill that I realised how much she depended on me”
Gill, 57**

Like Gill you may have started caring for your loved one long before they had a diagnosis of dementia. It may be that your loved one has not had a formal diagnosis but you have noticed that they are forgetful, or have difficulty with familiar everyday tasks. You may be concerned about safety in the home, or behaviour which is unusual for them. Changes in habits and behaviour are often very gradual but sudden changes are always worth investigating. It can be useful to have an idea of what to look out for:

Signs and symptoms of dementia

- Memory loss: We all forget things like keys and names but people with dementia may have complete absences and not remember anything later e.g. a visitor calling earlier in the day, or having had lunch.
- Inability to perform everyday tasks: A person with dementia may struggle with things that are second nature e.g. forgetting how to make a cup of tea.
- Disorientation in time and place: not recognising familiar places e.g. getting lost in places they know well, going to the shops in the late evening.
- Problems with words: Confused and muddled verbal communication, using the wrong words to describe things.
- Problems with thinking: This could be telling the time, or where abstract thinking is required such as not recognising what numbers or words on a page mean.
- Not realising when something is wrong: e.g. going out in nightclothes, regularly leaving main doors open or forgetting to light the gas.
- Changes in personality: Becoming suspicious, secretive, appearing depressed or constantly worried, taking unusual risks.
- Loss of drive: Needing prompting to wash, dress, eat or do things they previously enjoyed, or were conscientious about.
- Losing and misplacing things: e.g. putting slippers in the oven, bread in the laundry bin.
- Mood swings: Often with very little warning and for no obvious reason.

HOW DO I KNOW IF IT'S DEMENTIA?

Getting some people to go to the doctor can be a challenge, especially if there is a suggestion they may have problems with their mental health. It's often easier to suggest a visit to the doctor for some other reason e.g. a flu jab or blood pressure check where the symptoms described on the previous page can be discussed. It's a good idea to accompany someone who is experiencing difficulties, or to ask for a longer appointment when booking. It's not easy to suddenly get it all out in a brief consultation – especially if there is no one there to help.

There is no one test for dementia. It's a process of elimination. Your first stop should be the GP who can diagnose or rule out physical illness: tests for conditions such as thyroid problems, urine infections and reactions to other medication are common here. The GP will also check for signs of alcohol or drug misuse. In some cases the GP will also refer for or carry out blood tests and scans. Sometimes the GP will be able to make a diagnosis without extra scans. He will then help you access support through staff at the surgery. This may include a referral to Social Services for assessment and information and advice from a support worker at the Alzheimer's Society.

Following tests ordered by the GP some people will be referred to the Memory Clinic. Referrals can take a couple of weeks and they may carry out additional investigations such as more blood tests and scans before a diagnosis is made. It can take up to 10 weeks before the Doctors are in a position to confirm a diagnosis and begin future care planning, though you may be receiving help with urgent needs long before that. You will receive support from the Memory Clinic for up to six weeks after diagnosis before being returned to the care of your GP.

A photograph of two elderly women standing in a brightly lit room, possibly a community center or a shop. The woman on the left has short, curly blonde hair, wears glasses, a pink top, and a light-colored jacket. She is smiling and looking towards the other woman. The woman on the right has short, curly grey hair, wears glasses, a white top, and a dark purple shoulder bag. She is also smiling and looking towards the first woman. The background is slightly blurred, showing what appears to be a display case or a window with some items inside.

“It was very upsetting going through the process of diagnosis, although everyone was very helpful. It’s better now that we have a support plan.” Janet, 77

WHAT TO EXPECT AT THE MEMORY CLINIC

If referred to the Clinic your loved one may be seen by any number of people from a specialist team: doctor, nurse, occupational therapist or psychologist. They may have input to support the person following diagnosis; for example in helping you to manage challenging behaviour or in prescribing drugs to delay the progression of the disease.

Our Top Tips to prepare for assessment

Whether attending the GP or the Memory Clinic it makes sense to prepare well. These are our top tips for Assessment;

- Talk it through with your loved one: It's not easy to raise the subject and many people will be very upset at the suggestion that they are losing control of their faculties. It may take several conversations before they agree to see a doctor.
- As a carer you can help by attending appointments. You can make notes of what is discussed and add your input and experiences of the person.
- Keep a diary, or at least a note, of the things and symptoms that you have noticed.
- Be ready for lots of questions such as when you first noticed the problems, medical history, life events.
- Be ready for the reaction of your loved one who may be upset or offended by the thought that they are losing control.
- You need to be honest and sensitive about your feelings and needs too. If you need support to care say so.

Both carers and needs assessment are based on national agreed criteria for care and support. The assessor will focus on the things that you have difficulty with, any help you are already getting and what outcomes you want to achieve. This could include ways to help you stay in work, or get help with everyday chores.

Following assessment you will either qualify for a care and support plan or you will be signposted to agencies who can advise further. If you qualify for support you may need to contribute towards the cost of the care.

However much you love someone and want to dedicate yourself to caring for them it is important to recognise that you need to have some time for yourself. Even if you are in the best of health care, giving is demanding: you need to ensure you retain some balance.

Our Top Tips on caring for yourself:

- **Accept any help that is offered:** Whether it is from family, friends or professionals graciously accept all offers! Creating a support team (family, professionals or both) helps you access the help you need to care well.
- **Encourage family to become and stay involved in caring:** Don't exclude other family members, they want and need to help. If it isn't what you require, consider telling them what would help you most and ask them to find a way to resolve the problem.
- **Make plans:** An Emergency Plan is a must. You need to be methodical about recording everything that provides continuity for your loved one if you are suddenly unable to care. You also need to plan breaks, finances and how to get additional help.
- **Be realistic about the person you are caring for:** It is a progressive illness and they will deteriorate. Whether this is sooner or later is a very individual thing but he or she will change over time and this will impact on both your lives.
- **Look after your health:** Get a flu jab, try not to let stress build up, eat well, get enough sleep, don't ignore depression or low moods until it's too late.
- **Let your doctor know you are a carer – this is important for both you and the person you care for.** The doctor can, with your loved one's permission talk more freely about their health and wellbeing and you can be prioritised for flu vaccinations, appointment times.
- **Accept your emotions:** you will feel many things, often all at once. Negative feelings don't mean you are a bad person.
- **Share your feelings:** You may not like talking about your feelings but it can help. If you can't talk to people who you feel might judge you consider a telephone befriender or helpline where you talk to someone you never have to meet! You could also talk to a counsellor or refer yourself to the Luton Wellbeing Service IAPT team on 01582 393130 where you can be assessed for support.
- **Look for the positive:** You are doing your best and so is the person you are caring for. Enjoy what you can in each day, especially the funny and tender moments.
- **Take time out:** You will need to get breaks from caring: this could be lunch clubs, day centres, sitting services or respite care. It may also be asking family members to give you a break from caring. Taking breaks also helps the person who has dementia get used to and feel secure with other people so it's not selfish!



“Little breaks mean a lot to me, just doing normal things and meeting my friends and family helps me cope” Mary, 63

SUPPORT FOR CARERS

Even if the person you care for doesn't want an assessment of their needs you can still have a Carer's Assessment. Whether you care full or part time, live in or out you can still get advice on where to find help and practical support. You may also qualify for free carers breaks or allowances. Contact accessandassessment@luton.gov.uk or phone 01582 547659.

You can email the carerdevelopmentofficer@luton.gov.uk for information in getting involved in the Carers Partnership Board, or visit the council website www.luton.gov.uk

There are other services available locally to support carers, such as the Confident Carers Programme at the Disability Resource Centre. There are also a number of specialist peer groups for carers, including those from Asian and African Caribbean minority groups.

There are no local support groups for LGBT carers of people with dementia but you can access support through Age Concern Luton or LGBT Links. You can also view a directory of active LGBT organisations at www.lgbtconsortium.org.uk.

Full details of local support groups and addresses are available in the directory pages of this guide.

DEMENTIA FRIENDLY LUTON

Luton is working towards becoming a dementia friendly town. You may see people wearing the forget-me-not badge or displaying the logo in their premises. You can see more details about what is happening locally at www.luton.gov.uk/dementia or phone 01582 547646.

Many people in Luton have been to Dementia Friends awareness sessions including schoolchildren, health and care workers, local businesses, police, staff at restaurants, transport providers and local shop workers. We hope this gives you the confidence to get out and about in the town.

ENJOYING LIFE

Here are some ideas for having fun and keeping someone who has dementia occupied:

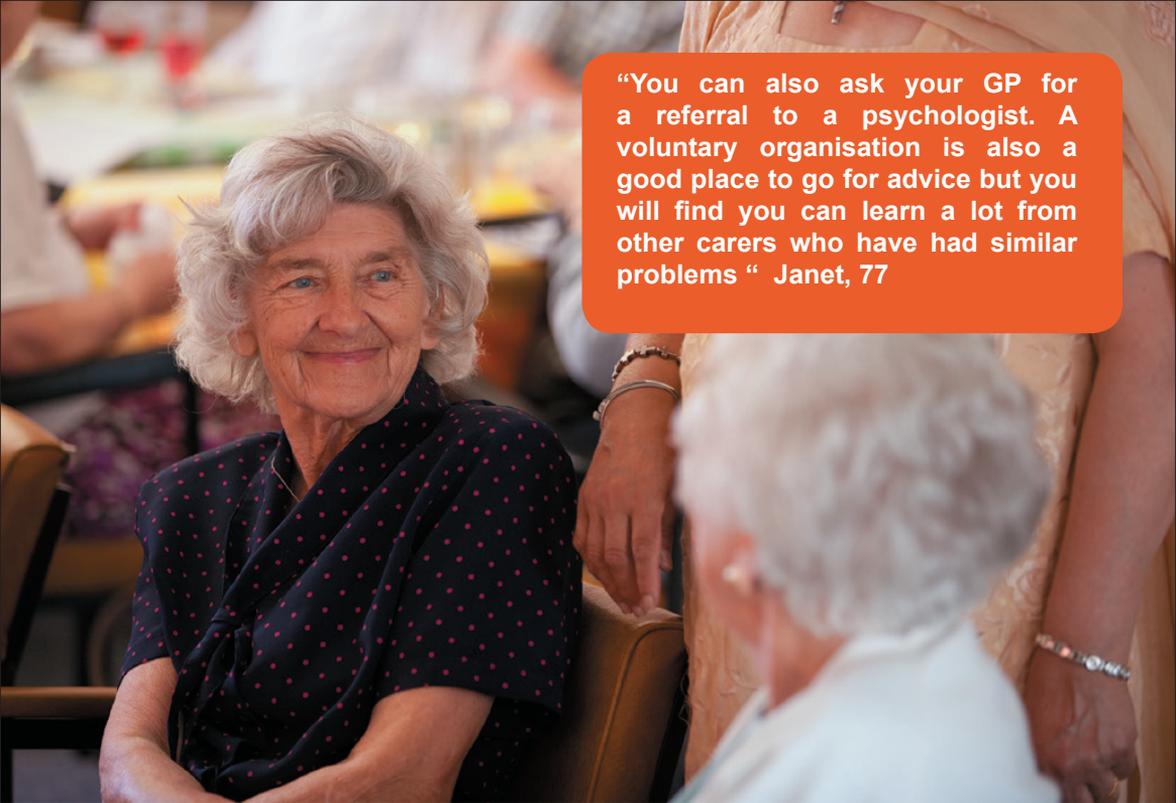
- Reminiscence: looking at photograph albums, old books or pictures and remembering can bring back great memories for both of you.
- A shared activity you both enjoyed: Dancing, walking the dog, gardening, cleaning or any physical activity may help sleep but sit-down activities are also great!
- Getting out and about locally: lunch clubs and music groups are brilliant for a change of scene and some respite!
- Opportunities for them to feel useful, e.g. helping with washing up or household chores if they are able.
- Meals and outings with friends and family.
- Hugs and cuddles – don't be afraid to remain affectionate if your loved one likes it. Affection can reduce anxiety and help you enjoy each other.
- Old films, TV shows and sports videos; e.g. watching a video of the 1966 World Cup victory together!
- Making a "This is Your Life" book or box together and filling it with photos and souvenirs that bring back happy memories.
- Carers also can get concessions such as free tickets to Luton Town Football Club (01582 416976), Hat Factory (01582 878100), Library Theatre (01582 547474) and Active Luton events when accompanying a disabled person. Check with each provider for current conditions.
- Don't ignore low moods: If they don't want to try anything, or one or both of you don't seem to enjoy anything, talk to your GP – there is no shame in admitting you may need a little extra help.

COMMUNICATION WITH SOMEONE WHO HAS DEMENTIA

One of the biggest challenges facing carers of people with dementia is communication with their loved one. It can be slow, frustrating and demoralising. Luton's carers offer the following tried and tested approach for good communication. If you can follow this plan you will reduce the potential for conflict. It goes without saying that it's best if you are relaxed - planning in advance is your friend and rushing is always your enemy!

Our Top Tips for communication

- Quiet and calm can help: some people can be confused and distracted by the TV or radio. If you are trying to communicate it can help to remove distractions.
- Take plenty of time: Try not to rush the person with dementia. Get attention by making eye contact and perhaps gently touching. Don't speak until you know you have their attention.
- Speak clearly using short sentences and wait a few moments for them to process your words before repeating yourself.
- Repeat if necessary – still smiling. Try not to get cross, but if you do say sorry and calm the situation down.
- Keep it simple: yes or no choices such as “Would you like soup or a sandwich?” are easier to answer for most people with dementia
- Accept they may not understand: they may be frustrated that they can't understand so respond and reassure.
- Demonstrate what you want where possible: show the car keys and the person's coat to let them know you are going out.
- Try again in a few minutes: If you don't get the reaction you want calmly leave and come back in a little while, they may be in a different place within a few minutes. Often there is a “best time” of the day for people with dementia. Your diary will help you identify this.
- Problem solve: If the person still doesn't understand take time to think how else you might communicate what you want. Many people with dementia find routines, prompting and reminders helpful e.g. laying clothes out in the order they are to be put on, brushing your teeth at the same time.
- Routine: Maintaining, creating and following routines can be reassuring, especially if these are routines the person has followed all their life.



“You can also ask your GP for a referral to a psychologist. A voluntary organisation is also a good place to go for advice but you will find you can learn a lot from other carers who have had similar problems “ Janet, 77

THINGS TO DO LOCALLY

There are a range of activities locally aimed at people with dementia and their carers. This includes education programmes, reminiscence activities, exercise classes, musical activities, day centres and lunch clubs. Age Concern Luton has an up-to-date list of local clubs and societies.

The best activities are those that someone has always been interested in such as sports, photography or any other pursuit. Many local groups continue to support members who now have dementia, so don't think you can only go to events for people with dementia. If the environment is safe and there are friends to watch out for someone there's no reason for them to stop doing what they love.

Finding a way to keep people engaged with their own friends is good for their health and provides much needed support to the carer – the benefits of laughter with friends cannot be overestimated!

HOLIDAYS AND INSURANCE

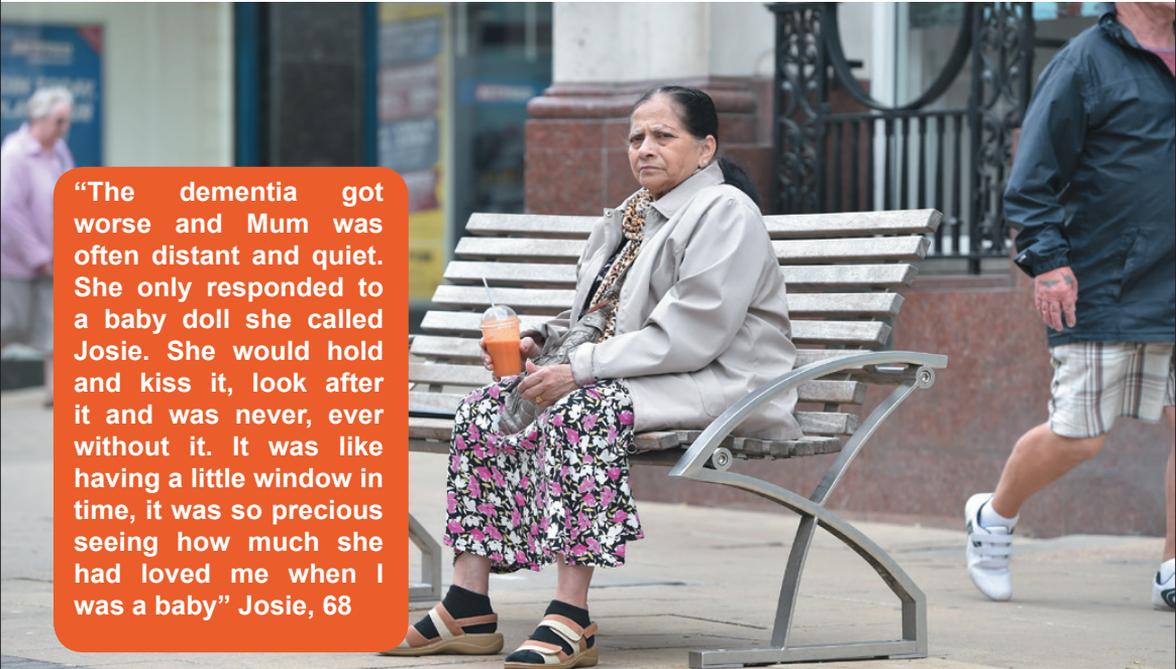
It's important to let your travel insurers know that there is a person with dementia in the party; there are specialist insurers who cover the condition. Alzheimer's Society has information on holidaying with people who have dementia.

CHALLENGING BEHAVIOUR

As the disease progresses it may be difficult to stay engaged with people who don't understand why someone is behaving the way they do. It may be that the person with dementia is overwhelmed or frightened and this can lead to difficult behaviour or panic attacks. It's worth reminding others that staying calm usually helps and most of the time the person with dementia will settle quickly.

Finding an activity that soothes is useful. For some people, especially those who like fiddling with things, fidget boards with locks and bolts, or quilts of different colours and textures can be useful to help distract and occupy anxious people. Others will find favourite books, music or just giving a hug can also work well.

If you would like to find out more about fidget boards or activity quilts contact Age Concern Luton - the address is at the back of the book.

A photograph of a woman with dark hair pulled back, wearing a light grey jacket and a floral patterned skirt. She is sitting on a wooden park bench with a metal frame, holding a clear plastic cup with an orange drink. She has a serious, somewhat sad expression. In the background, there is a blurred street scene with other people walking. A man in a dark jacket and shorts is walking past her on the right. Another person is visible in the background on the left.

“The dementia got worse and Mum was often distant and quiet. She only responded to a baby doll she called Josie. She would hold and kiss it, look after it and was never, ever without it. It was like having a little window in time, it was so precious seeing how much she had loved me when I was a baby” Josie, 68

COMMON HEALTH PROBLEMS AND WHAT TO DO ABOUT THEM

Someone who has dementia may not be able to communicate how they are feeling so it helps to be vigilant about signs of ill health. In general if you notice any sudden change or decline it is worth getting it checked out.

Our Top Tips for health

- Something different could be a sign of pain or infection e.g. hallucinations, swearing, seeming anxious or more disconnected than usual, even a change of facial expression could all be signs of pain or illness.
- Anticipate pain if you know they have a painful condition, don't wait for them to show the signs. Ask your GP or nurse for advice on pain management.
- Routines can help when it comes to stoma care. You need to ask the person with dementia to allow you to help, or to consider having care workers at as early a stage as is possible.
- Wound care, e.g. for leg ulcers can be painful. Make sure the person has painkillers before the wound is dressed.
- Some medications and medical conditions can increase the risk of falls. Discuss this with your GP. The Falls Service can help reduce the risk of serious injury in the home.
- Incontinence can be a sign of a curable health problem, constipation or simply the disease progressing. Your GP needs to know and can refer you to the continence service for more advice and help with pads.
- Constipation (whether from bowel disease, other medical conditions or medication) benefits from gentle exercise, increased fluids and plenty of fibre. Good skin care for people who are incontinent is crucial to avoid pain from rashes. Damaged skin can lead to pressure sores and should never be ignored.
- Reduced appetite could indicate problems in the mouth and again you can refer to the GP for investigation. Snacking on small finger foods can be more appealing than a big meal for many people.
- People with dementia may become frail, especially if they are older. Watch out for weakness, low energy and loss of more than 10 pounds in a year. General frailty increases the risk of harm from falls and infections.
- If in doubt check it out! There is nothing to be gained from ignoring issues or hoping things will clear up by themselves. If you are worried you can call 111 or book an appointment with the GP. Your own peace of mind is important as well!



“I live alone and have four life threatening illnesses so dementia is just something else to contend with. I’ve already planned as best I can so I just take each day as it comes” Tony, 74

HOME SAFETY

Living alone safely with dementia

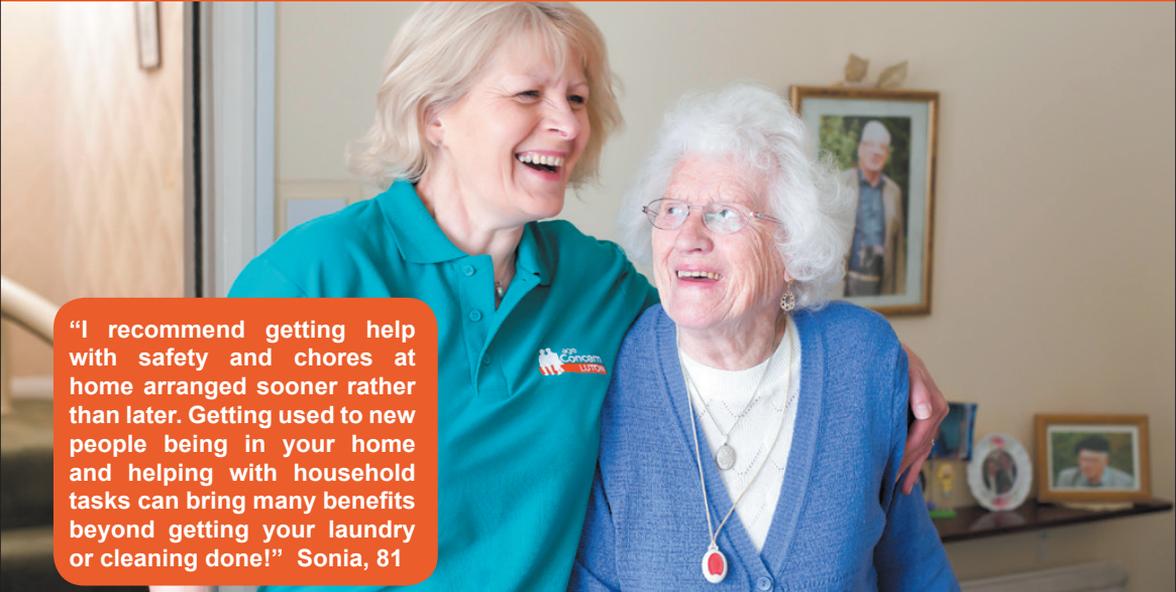
Many people continue to live safely at home in the community for some time after a diagnosis of dementia. They will need support; for example good neighbours or family dropping in regularly. If you don't have anyone who can do that it's a good time to start creating new networks. Following diagnosis you will be offered support from Social Services and voluntary agencies: accept all the help you are offered because it will help you stay independent for longer.

You will probably find that you are contacted by people from various agencies about many different things; assistive technology, help with personal care, falls prevention, benefits advice, help to make your home safer. You don't have to accept everything the minute it's offered but it helps to know what is available and how you can access these services.

There is a list of organisations providing help at home at the end of this guide.

Our Top Tips for improving safety

- Get a pendant alarm – we recommend telelinkservices@luton.gov.uk - peace of mind for around £3 per week.
- Install a keysafe: These simple devices are operated by a pin code and hold a key. You can buy them or ask your care team about having one installed by Age Concern Luton who keep a secure record of all pin codes and maintain them for free.
- Maintain balance between safety and a comfortable place to live. Too many changes can be disorientating for some people with dementia.
- Consider falls risk: poor eyesight or reduced perception can increase falls risk so use brighter light bulbs, clear passageways and stay alert to hazards.
- Increase contrast between floors and walls and clearly define steps.
- Install handrails near steps, in hallways and in the bathroom. Occupational therapists, The Falls Team or Age Concern Luton can all help.
- Gas fires and hobs are potential hazards; they can be disabled if necessary.
- Fit a fire alarm. The Fire Service can do this for free
- If you're not living with the person you care for ensure you call in regularly and ask neighbours, local shop keepers, community organisations and regular callers such as the postman to keep an eye on the person living alone and report anything worrying.
- Alert the Police if the person is known to wander. Call 101 and ask for the Community Policing Team.



“I recommend getting help with safety and chores at home arranged sooner rather than later. Getting used to new people being in your home and helping with household tasks can bring many benefits beyond getting your laundry or cleaning done!” Sonia, 81

HELPFUL TECHNOLOGY

There are many devices designed to help people feel safer at home. These include alerts such as pendants worn around the neck or as a wristwatch, and programmed alarms to remind people to take medication or to close the door. Some of these devices take a lot of practice and it can be difficult for some people to learn how to use them. If you are interested in these aids the Disability Resource Centre. 01582 470900, may be able to advise you further.

SHELTERED HOUSING

You may decide that it's time to move to sheltered housing where staff members are available on site if you need someone to watch out for you or provide immediate support. You will need to apply to the local authority before you can bid on suitable properties. Sheltered housing is not the same level of care as a care home, though some 'extra care' schemes have carers available to help the residents. You can discuss your housing needs with any of the professionals involved in your care and ask them to refer you. You can still apply for sheltered housing even if you own your own home.

There are also housing associations and private sheltered housing schemes in Luton but not all of them cater for people with health needs. Age Concern Luton can help signpost you if you are interested in this option or you can contact the Elderly Accommodation Counsel on 0800 377 7070 for details regarding all housing and care home options for older people.

Tenancies

Where carers live with someone who has dementia it is wise to check their position in the event of the person they care for leaving the property. It is worth speaking to your Housing Officer if you have one, or contacting the Housing Solutions team at the council. They operate a drop-in service from Monday to Friday but can also be contacted via email - homelessprevention@luton.gov.uk or by phone on 01582 510370. You can also get housing advice from the Citizen's Advice Bureau, or Age Concern Luton.

LEGAL AND FINANCIAL MATTERS

Once you have got over the initial shock and grief of diagnosis it makes sense to try to plan ahead. Ideally all family members will be involved with this. You need to plan for emergencies: who will care if you get ill? You need to think about financial matters – property, benefits and work if you are still in employment. You need to think about your living arrangements, legal and financial matters, getting help from care agencies and the role of family members in providing breaks and support.

Because people with dementia lose the capacity to make decisions they need to make sure that they sort out these important matters as soon as possible. Once these decisions are made and plans are put in place there is peace of mind for all concerned. It's a good idea to speak to a solicitor as soon as possible.

Appointeeship

This is often the simplest way to handle someone's financial affairs and is ideal if they are on a low income. The family or carer can nominate one person to receive and spend the person's benefits. The DWP will visit to assess whether to grant appointeeship and there is no charge for this.

Lasting Power of Attorney (LPA)

There are different kinds of Lasting Power of Attorney: one is for people appointing someone to make decisions about their property and finances and the other relates to decisions about medical treatment. The second can only be used if the person can no longer make his or her own decisions about their medical care. The person whose affairs are to be managed is called the "Donor".

You can apply online for Lasting Power of Attorney by visiting www.lastingpowerofattorney.service.gov.uk but many people seek advice from a solicitor or an organisation such as Alzheimers Society. Completed forms need to be sent to the Office of the Public Guardian to be registered and are only valid when accepted. It costs £110 to register each type of LPA but is free to Donors on certain means tested benefits.

Donors whose income is less than £12,000 per year before tax are charged £55. Full details are available from the Office of the Public Guardian website or by phone on 0300 456 0300 (textphone 0115 934 2778).

Court of Protection

If someone has not set up an LPA the family or carer can apply to the Court of Protection for permission to make decisions on their behalf. The person applying on behalf of someone who cannot manage their affairs is called the Deputy. There are different kinds of deputies for health and welfare decisions and financial decisions. It's expensive to register (currently £400) and if a hearing is required another £500. The Deputy has to register and there is a fee of £100 for new deputies. There is also an annual fee to pay for supervision which can be between £35 - £320 depending on which categories the Deputy is responsible for. You can find more information at: www.gov.uk/apply-to-the-court-of-protection or by phone at 0300 456 400.

User controlled trusts

This is known as an independent living trust. It can be set up before dementia progresses while the person can still make choices about their money and care. It can be used as a way to manage direct payments and other benefits. A minimum of two trustees is required and it is essential to get advice from a trusted source such as a solicitor before proceeding. You can find out more on the www.moneyadvice.service.org.uk website.

Advance decisions

This is a signed and witnessed record to cover matters relating to medical treatment, which might include blood transfusions or resuscitation. These can only be made where someone still has mental capacity. Advance decisions are legally binding on medical staff. This will be discussed with you at the Memory Clinic but you can raise the matter with your doctor at any time. Many GPs will assist in helping patients think through the options.

Advance statements

These are not legally binding but generally speaking are statements of wishes about the general kind of care people would prefer. This is helpful where there are several family members who cannot agree on aspects of care. Most doctors and care workers aim to ensure your wishes are followed as closely as possible. You can find out more on the www.nhs.uk/planners/end-of-life-care webpages.

Wills

Wills are only valid when someone has capacity at the time they are made. It is wise to speak to a solicitor, especially when you own property or have complex family relationships.

You may be able to get your will at a discounted rate through your employer or Trade Union. There are also local solicitors in Luton who take part in free wills month when you make a donation to charity in return for having your will drawn up. This is usually in October or November and you can find more information at www.willaid.org.uk.

If you don't have much money and your wishes are quite straightforward you may want to consider a simple do-it-yourself will. You can buy kits in high street newsagents for around £15 or visit www.moneysavingexpert.com for free templates.

DRIVING AND TRANSPORT

Criticising someone's driving is a sure fire way to spark a major disagreement in any relationship! It can be very difficult to accept that you are no longer safe on the road and many people resist going to the GP for fear of losing independence, including their licence to drive. Many local carers found this was a major point of conflict with their relatives and have provided some tips for bringing up the issue on the page opposite.

The Law and insurance

If someone has been diagnosed with dementia, or mild cognitive impairment they must inform the DVLA and their insurance company. The DVLA will ask for a report from the Memory Clinic and/or the GP before deciding whether the person should surrender their license. If the licence is not withdrawn it is likely to be reviewed in a short period, between 1-3 years.

If you have a diagnosis of MCI or dementia you may still be able to drive but be unable to get affordable insurance. You can get up to date advice on this from disability groups or insurance brokers.

Side effects from cognitive enhancing drugs may impact the ability to drive safely and this also needs to be taken into consideration by all concerned. You can also book an Independent Driving Assessment at Welwyn Garden City 01707 324581 where overall road safety can be assessed.



“I’ve always said I’d rather lose my legs than my driving licence but my Personal Transport Plan has softened the blow. I can still get out and about, even though I don’t have the freedom to just jump in the car” John, 81

Our Top Tops for giving up driving

- If you know that raising the subject will cause distress choose your moment carefully and be well prepared. Raising the issue sooner after diagnosis rather than later when the disease is progressing is likely to get a better response.
- Point out the advantages in not driving: lower costs, no parking worries, and many other cheap and convenient methods of transport.
- Express your own worries if the person is receptive: road safety, too much traffic, nowhere to park, too expensive for the few miles they do.
- Ideally work with them to sell the car together as early as possible and establish new transport routines.
- Speak to other friends or family involved in caring for the person and see who can offer lifts or help with shopping and other tasks
- Speak to an Age Concern Luton advisor on creating a fully costed Personal Transport Plan for the person with dementia
- If they are unsafe and won't stop driving consider disabling the car, or moving it off the premises.
- Cancel subscriptions to the AA, RAC or recovery services and make them aware of the driver's situation.
- If someone is worried or distressed about their car being missing consider a cover story they will accept e.g. "I took it to the garage for it's MOT"
- If you remove the car tell the Police that it has not been stolen – this is vitally important!

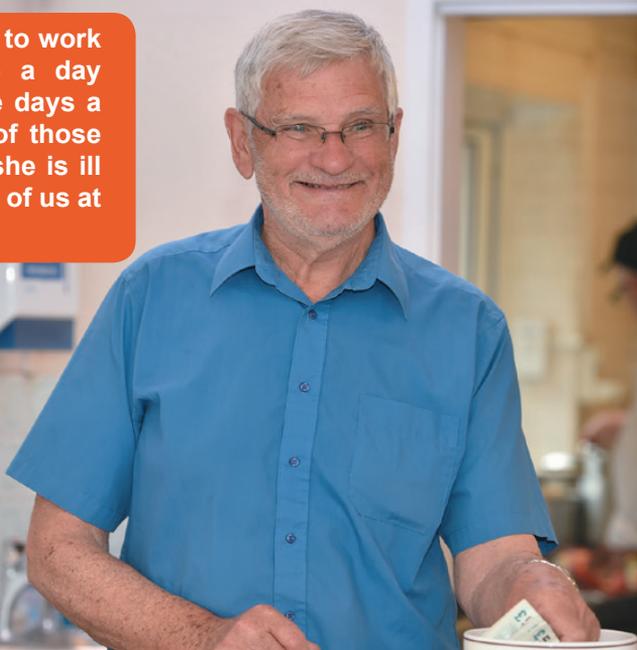
Personal Transport Plan

Although the DVLA may not immediately withdraw the licence both the person with dementia and the carer should still discuss whether giving up driving is the right option. Moderate to severe dementia will always result in loss of driving licence. Although this is hard to discuss it is essential to have a transport plan. There are options available including Blue Badges, Dial-a-Ride, Shopmobility and volunteer drivers but it's important to discuss your individual needs first. Call Age Concern Luton on 01582 456812 for more advice.

Blue Badges

In most cases people with dementia will not automatically qualify for Blue Badges, though people who are on the enhanced rate of PIP should always be eligible. Badges are awarded for three years before review. A carer can apply on behalf of a person with dementia by requesting the form from Customer Services at Luton Borough Council. A high percentage of applicants will have an interview with a council officer and Age Concern Luton can help you with filling in the form.

“I enjoy my job so I asked to work part time. Mum goes to a day centre or lunch club three days a week and I work on two of those days. I have a plan for if she is ill and it’s working well for all of us at present.” Gary, 62



WORK AND DEMENTIA

If someone diagnosed with dementia is still in work he or she will probably want to discuss this with their employer. Some people are happy and able to continue in their role and their employer may be able to offer some flexibility to help them stay in work. They can get advice from their doctor, or the Memory Clinic about how dementia will affect them in their job. It may be that they want to consider early retirement and they will need to get advice on this. Trade Union officials, occupational health and HR officers are good sources of help. They could also consider talking to a local agency such as Luton Rights on 01582 453372 or the Citizens Advice Bureau on 0344 245 1285 who are also able to provide information on entitlement for benefits if they are unable to carry on with work.

Dementia does not necessarily mean the end of a working life; some people still volunteer their time or carry on with paid work.

Our Top Tip

Put your emergency contacts into your mobile phone under “ICE”. This stands for “in case of emergency” and the term is known to the emergency services. It will help identify your best contacts easily.

Working carers

If you are still working and need time off to deal with an emergency you are entitled to do so, although whether you are paid is at the discretion of your employer (unless explicitly stated in your contract of employment or staff handbook). You are also entitled to ask for flexible working, which may include working from home, shift swapping or some other arrangement. Your employer should give reasonable consideration to this but is not obliged to grant your request if there is a sound business reason to refuse it. If you are a member of a Trade Union you may ask for support in making your application, or you can get advice from the Citizens Advice Bureau or Luton Rights.

These organisations may also be able to assess you to see if you are eligible for benefits. This can help you make an informed choice of how giving up or reducing work will affect you financially.

If you belong to a Trade Union or professional body they may allow you to stop or reduce payments if you are reducing your hours or taking time out to care for someone. We recommend that you contact these bodies directly to discuss your options.

Under the Care Act 2015 the council has a responsibility to assess your need for support, this could entail helping you stay in employment. Be sure to mention this at your Carer's Assessment.



“I realised I needed to make a better plan for Mum’s care when I was rushed to hospital and ended up staying in for 7 days” Linda, 66

HOSPITAL

If you live in Luton it's likely that you will need to visit the Luton & Dunstable Hospital at some point, whether as an out patient or for a longer overnight stay.

Our Top Tips for carers who are going in to hospital

- Tell all the people who are involved with your and your loved one's care that you are going into hospital
- If you don't already have help with caring you need to ask family, friends and possibly Social Services. It's easier if you think of the tasks that need doing and who is best to help, so prepare for the conversation.
- If you have been keeping a diary or notes of the routine of the person you care for, as well as their likes and dislikes, it will be much easier for others to support them while you are away.
- Leave time for recovery; you may need to think about ongoing treatment, a period of convalescence and whether you will be fit enough to care.
- Consider whether you want to have visits from your loved one – this can be reassuring for both of you but it could also be upsetting and stressful.
- If you want visits consider who is best to take your loved one and ask them.
- Be open minded about the help that is available. Even if respite care, or care workers did not work as well as you hoped in the past it may be worth reconsidering.
- Accept help! Be honest about your own needs and what feels too much for you.
- Plan for discharge: you can get a free guide and day of discharge support from Age Concern Luton on 01582 456812.
- Remember that routines may change after a break and there may be a period of settling back in when you get home.

Luton & Dunstable Hospital support for people with dementia

The L&D have a dementia nurse specialist whose role is to promote the best care for people with dementia while in hospital. You can phone her on 01582 498806 or 491166 between 9-5 each weekday or email her: Yvonne.weldon@ldh.nhs.net. There are dementia champions in most wards and departments of the hospital – they wear a badge and so are easily identifiable (if you can't see anyone wearing this badge a member of staff should be able to get them for you!).



“Mum would do whatever I needed her to do but only if I apologised before asking! It was as if this gave her the chance to be the one who was in charge” Sandra, 73

The Hospital staff will encourage you to complete a short booklet called “This is Me” which is basically a biography of the person with dementia and a series of prompts about his or her routines, likes and dislikes and other important information. Taking the time to do this can really help others communicate in a way which is comforting to your loved one, especially if they are anxious and unwell.

It’s really important to let the staff know whether your loved one needs support with eating and drinking and whether, for example, they tend to wander. Information about the daily routine may help identify whether they are likely to be unsettled at night or whether there is a best time of day for being co-operative with tests and procedures.

It is also worth discussing extended visiting hours as it may be beneficial to both your loved one and hospital staff if you are on hand to help with communication and emotional support.

If you are visiting as an outpatient you may need to ask about transport and parking if this is likely to be a problem for you. Some clinics can offer a degree of flexibility on appointments as they understand how difficult it can be to get people with dementia out of the house for a particular time.

Luton & Dunstable Hospital has a team of geriatricians who are specialists in the care of elderly patients with complex problems, including dementia. They understand that it can be difficult to ensure tablets and treatments are taken as prescribed when someone has dementia so don’t be worried about being open and honest about any problems you are having in caring for your loved one. They do understand.

Advisors from the Alzheimers Society are available for general support and advice - you can call them on 01582 490190 on any weekday.



“Get a benefits check and claim: our income increased by nearly £200 a week which meant I could afford all the help I needed to care well for her” Rex, 84

Paying for care

If the person you look after has a care agency helping them or attends a Luton Borough Council daycentre they will have a financial assessment which goes into a lot of depth. Many people worry about this because they don't really understand how the council works it all out.

Despite the plethora of information available it's generally quite straightforward. You are allowed a basic minimum income of £131.75 for single people aged under 64 and £189.00 for those aged over 65. This is calculated by adding up all your income including benefits, savings and earning from property. They deduct basic housing costs, living expenses and some other costs. If your income is too low you won't pay anything towards your care. If it exceeds the figure above you pay on a sliding scale up to a maximum of £334.50 per week.

Some services provided by the council are chargeable; they include Day Centres (£14.75 per day) and Home Care (£14.75 per hour). Others are non chargeable: this includes sitting services of up to four hours per week, OT equipment and help from the Reablement team or intermediate care for up to six weeks.

Paying for residential care

If someone goes into care another assessment will be undertaken, this assessment is similar to the above but also takes into consideration the value of any property they own. People going into care may qualify for additional financial help from the NHS in the form of continuing healthcare or NHS-funded nursing care. This can be discussed with your GP, or any social or health care workers advising you.

Self-funding care

People who have savings of over £23,500 are considered to be self funders for all chargeable services, whether in the community or in residential care (though this includes all assets). This will rise to £27,000 for people receiving care in the community and £118,000 of capital if you are in a care home from April 2016.

You should still consider having a financial assessment as you may be eligible for council funded care and support if your income is lower than the basic minimum income for someone your age (this is £131.75 for single people aged under 64 and £189 for people aged over 65). It will also help you identify when you are likely to qualify for additional allowances or financial assistance.

Having an assessment is always a good idea as you will benefit from advice and support of council staff who have experience in arranging care and support. They can help you to find local services, or placements in care homes.

Cap on care costs

In 2016 we are likely to see a life-time cap on how much people pay towards their care as it is one of the Government's proposals within the Care Act. There is no figure on this yet but you should be able to contact any local advice organisation nearer the time in order to find out.

Deferred payment agreements

If someone goes into residential care they can enter into an agreement with the council to defer payment until their home is sold, even if this is after their death. This may be useful for some people, especially if they anticipate returning home at some point in the future.

Benefits and allowances

Calculating your entitlement to benefits and allowances can be complex. It makes sense to get a full check from an experienced person. There are several organisations in Luton who can help you claim everything you are due. Age Concern Luton have workers who specialise in benefits for older people and carers but you can also get help from the Citizens Advice Bureau, Luton Rights and others.

Attendance allowance

This is a benefit for people aged over 65 who have serious physical or mental disabilities. It is currently paid at £55.10 per week (lower rate) and £82.30 (higher rate) for people who need help day and night. Attendance Allowance is not means tested. You are not able to receive Attendance Allowance if you also receive DLA or PIP.

PIP

This benefit replaces the Disability Living Allowance for those aged under 64. You can get between £21.80 and £139.75 each week depending on the assessment of your entitlement.

Carer's Allowance

You must be aged over 16, earn less than £110 per week after tax and spend at least 35 hours per week caring to qualify for this benefit. The person you care for must be in receipt of PIP, DLA or AA and you may not qualify if you are in receipt of other benefits, including retirement pension.

Council Tax Discount

You may qualify for a reduction in Council Tax if you are a live-in carer but not the partner or spouse of the person with dementia. Other discounts may apply, such as single person discount (25%) or reductions relating to disability.

Direct payments and personal health budgets

Only people who have been through a Needs Assessment or Carer's Assessment can qualify for a Direct Payment. Following assessment you will be contacted by an advisor from the Disability Resource Centre who will give information on the support they can provide to administer the scheme.

You can choose to have a direct payment instead of letting the council organise services for you.

You can't be forced to take a direct payment and you can change your mind if you decide later that you would like to try it out.

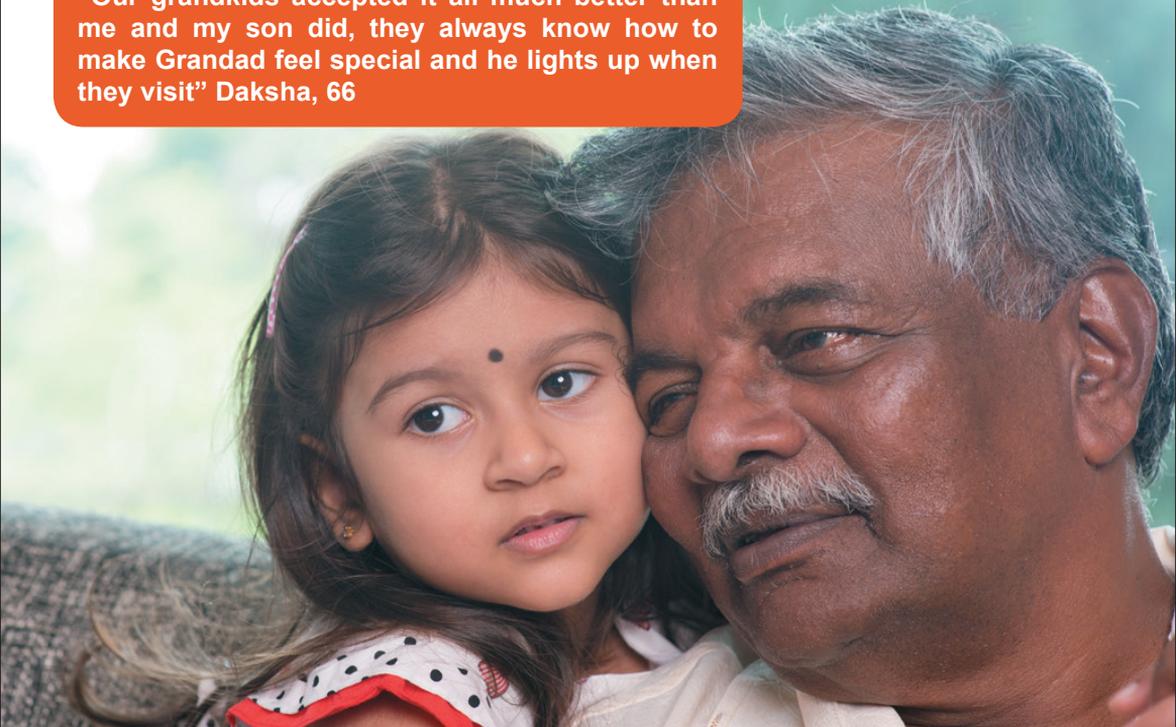
Some people let the council organise some services, such as care workers and retain part of the budget for other things such as social needs. Any payment for services organised by the council would be deducted from the overall personal budget.

Payments can only be spent on items which are part of the assessed needs. People receiving direct payments will have an annual review of their needs.

Some people feel that a direct payment gives them more choice and control, for example they can employ a care worker of their choice rather than rely on staff from an accredited agency. However you cannot employ family members who are living in the same household as you.

Similarly people who have had an NHS assessment may qualify for an NHS Personal Health Budget - you can find out more at www.nhs.uk/personal-budget.

“Our grandkids accepted it all much better than me and my son did, they always know how to make Grandad feel special and he lights up when they visit” Daksha, 66



DIRECTORY OF SERVICES

Local Health and Social Care Providers

Cambridge Community Services NHS Trust— providing community health services for adults including Falls Service, palliative care, District Nurses and Community Matrons, Acute Care Community Team (by referral only)
0333 405 3000,
www.cambscommunityservices.nhs.uk

East London NHS Foundation Trust – providing Mental health and Wellbeing Services including Memory Clinic and talking therapies for all Luton adults (by referral from Health or Social Care professional).
0330 124 1771, www.elft.nhs.uk

Luton Borough Council – For all services including needs and carers assessments
01582 546000,
www.luton.gov.uk
(self referral always welcome)
On the website please select 'Health and social care' and then 'Adult Social Care' and then 'Being a carer' for a host of useful information and links

Customer Service Centre
01582 547659 or 01582 547660

Blue Badges—permit to park in disabled bays.
01582 547272,
e-mail: bluebadges@luton.gov.uk

Luton Clinical Commissioning Group – GP led organisation who plan, organise

and purchase NHS services for Luton
www.lutonccg.nhs.uk Patients Advice And Liaison Service 01582 510373
pals.lutonccg@nhs.net

South Essex Partnership Trust (SEPT) - providing continence services in Luton (by referral from GP or Health/Social Care professional only)
www.sept.nhs.uk/continence

Virgincare – intermediate care rehabilitation therapists who help patients achieve as much independence as possible following serious illness (by referral from health and social care professionals)
01582 709067 www.virgincare.co.uk

Local Organisations

Age Concern Luton – advice & information, help to claim benefits, cleaners, laundry and handymen, carer support, lunch clubs & befriending, support on leaving hospital, personal transport plans, transport. Self referral welcome.
01582 456812,
www.ageconcernluton.org.uk

Active Luton—local providers of swimming & sports centres offering a wide range of activities. Self referral welcome.
01582 400272, www.activeluton.co.uk

DIRECTORY OF SERVICES

Alban Neve Deaf Association
E-mail: info@andaluton.org.uk

Alzheimer's Society (Bedfordshire & Luton) – Caring local Support Workers to advise and support you from diagnosis and beyond. Carer education programmes and support groups, activities including singing and cognitive stimulation to improve communication and confidence.
01582 470910

Bedfordshire African Community Centre –support for the welfare of African people living in Bedfordshire
01582 484807, www.africancentre.org.uk

Citizens Advice Bureau – Free confidential advice available by telephone or appointment, advisors are fluent in many community languages. Areas of advice include housing, employment, legal and financial problems.
0344 245 1285, www.lutoncab.org.uk

Cruse Bedfordshire— confidential bereavement support in groups or one to one. Self referral is always welcome.
01582 595300,
www.crusebedfordshire.org.uk

Disability Resource Centre – Dunstable resource centre with workers who can help with direct payments, equipment advice, and home of the Confident Carers network.
01582 470900, www.drcbeds.org.uk;
confidentcarer.org.uk

Headway Luton—supports adults of all ages who have had brain injuries. Daycentre offering art, computing and social activities in Luton town centre.
01582 876729, www.headwayluton.com

Keech Hospice Care – care and support for wellbeing at the end of life and after bereavement.
01582 492339, www.keech.org.uk

Luton Asian Carers Service— Culturally sensitive carer support for people from the Pakistani/Kashmiri, Bangladeshi, Hindu and Sikh communities. Self referral welcome, 01582 519500 www.cycd.org.uk

Luton Cultural Services Trust— Museums & Libraries service offering helpful resources such as reminiscence boxes and “Books on Prescription” for dementia patients and carers.
01582 547470, www.lutonculture.com

Luton Law Centre—Free Legal Advice & Representation on Immigration, Asylum, Community Care, Debt and Housing problems.
01582 481000,
E-mail; admin@lutonlawcentre.org.uk

Luton Rights—Free Welfare Benefits & Employment advice,
01582 453372

Luton Shopmobility—Scooter loans, transport & escorted shopping,
01582 738936

DIRECTORY OF SERVICES

LGBT Links Luton – Support and healthy living for lesbian, gay, bisexual and transgender people,
LGBTlinksluton.org.uk

Mind BLMK— activities & support promoting mental health recovery and wellbeing,
01582 757625,
www.bedsandlutonmind.org.uk

Music24 – making music for people with dementia.
www.music24.org.uk

Parkinsons UK Luton & District Branch:
01525 838543, jlewin@talktalk.net

Pohwer—Advocates for IMCA (referral only), self referral welcome for IMHA, Care Act , Community Advocacy and NHS complaints.
01582 447109, 0300 456 2370,
www.pohwer.net

Sight Concern Bedfordshire – Talking newspapers, IT training, visual impairment advisors, Benefits Advice and Luton resource centre to support people with sight loss.
01582 655 554
www.sightconcern.org.uk

Singing Café – Free sing song and dancing for carers with cared for.
Sundon Park Baptist Church , Friday 10.00 – 11.30 am. 244 Sundon Park Road, Luton, LU3 3AL.
01582 576974

Singing Café – Free sing a long for carer with cared for.
Stopsley, The Green House, St. Thomas Road, Luton – 10.00 – 11.30 am. – Jane Butler 01582 401480

South Beds Dial-a-Ride—Door-to-door dementia friendly transport for disabled and vulnerable people.
01525 220044

Stroke Association Luton – Support and advice for people who have experienced strokes and their carers.
01582 891330,
Email: Rebecca.chatterton@stroke.org.uk

National Organisations

Action on Addiction
0300 330 0659,
www.actiononaddiction.org.uk

Action on Hearing Loss—formerly RNID
0808 808 0123,
www.actiononhearingloss.org.uk

Age UK
0800 169 6565, www.ageuk.org.uk

Alzheimer's Society
0300 222 1122, www.alzheimers.org.uk

British Heart Foundation
0300 330 3322, www.bhf.org.uk

Carers UK
0808 808 7777, www.carersuk.org.uk

Diabetes UK

0345 123 2399, www.diabetes.org.uk

Down's Syndrome Association

0333 1212 300,
www.downs-syndrome.org.uk

Epilepsy Society

01494 601 400
www.epilepsysociety.org.uk

Independent Age – advice line and resources for older people.

0800 319 6789
www.independentage.org

LGBT Consortium –signposting for lesbian, gay and transgender people,
www.lgbtconsortium.org.uk**Macmillan - Cancer Care and advice,**
0808 808 0000, www.macmillan.org.uk**Marie Curie**

0800 716 146, www.mariecurie.org.uk

Mencap

0808 808 1111, www.mencap.org.uk

Multiple Sclerosis Society

020 8438 0700, www.mssociety.org.uk

Mind

0300 123 3393, www.mind.org.uk

The National Autistic Society

020 7833 2299, www.autism.org.uk

Parkinson's UK

0808 800 0303, www.parkinsons.org.uk

Rethink Mental Illness

0300 5000 927, www.rethink.org

Royal National Institute of Blind People (RNIB)

0303 123 9999, www.rnib.org.uk

Samaritans

08457 90 90 90, www.samaritans.org

Scope - disability charity for cerebral palsy

0808 800 3333, www.scope.org.uk

Spinal Injuries Association

0800 980 0501, www.spinal.co.uk

Terrence Higgins Trust - HIV/Aids information,

0808 802 1221, www.tht.org.uk

The Stroke Association

020 7566 0300, www.stroke.org.uk

If you have any comments, complaints or compliments regarding this guide please get in touch with us at:

Luton Dementia Guide
Age Concern Luton
Bradbury House
39 King St
Luton
LU1 2DW

or via e-mail:

carers@ageconcernluton.org.uk



“Never think there is no-one who wants to help and support you” Roy, 91

This is a unique guide, commissioned by Luton Borough Council and written by people with dementia and those who care for them.

We have included all our Top Tips for looking after yourself and we hope that these are as useful for you as they are for us. This is the knowledge you need, even if you don't know it yet! We are not concentrating on what dementia is or any of the science. There are plenty of good fact sheets out there with that kind of information. This is different: it's about how we found a way to live as well as possible with dementia in Luton today. We've presented this as a series of Top Tips for ease of reading and all the information is local. If you are reading this outside Luton the top tips will still work but we recommend you contact your local Social Services department for organisations in your area.

DAA

Luton Dementia Action Alliance

Luton Dementia Guide 2015

In partnership with

