



Living well at home with **dementia**

Foreword

Receiving a diagnosis of dementia, experiencing memory loss or changes to your behaviour can be frightening and overwhelming. Similarly, caring for someone with dementia can be a demanding task.

This booklet is for people with dementia, their families and carers. It offers possible solutions for the current and potential issues that may arise in and around the home. For example, do you have concerns about the person with dementia's ability to return home after a walk? Some of the suggestions may be useful, others may not, you choose what works for you.

Possible sources of further help and advice are given and some practical solutions are suggested.

The key message in this booklet is that you don't have to do it on your own. There is help available from health and social services, voluntary organisations, and charities such as Alzheimer Scotland. A number of useful contact details are listed on page 16.

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Accessing your home

Front / Back access

- **Difficulties getting in/out of the house?**
- **Difficulties opening or answering the door?**
- **Does the person with dementia go out and get lost?**
- **Do you hold/hide keys to prevent the person with dementia leaving the house? (Note that this may contravene their Human Rights and have implications for their safety).**
- **Are there supportive neighbours who can advise someone if the person with dementia leaves the house?**
- **Is there a busy road, expanse of open water, or other hazards nearby?**
- **Do you have concerns about the person with dementia's danger and road safety awareness?**

Consider... *(in no particular order)*

- We know that well lit steps, footpaths & porches can help avoid trips/falls and grab rails and/or handrails over the steps can provide support.
- WLC's Occupational Therapy Self Selection Service can provide grabrails and/or handrails.
- West Lothian Council's (WLC) Home Security Scheme can provide a door intercom; security lighting; and/or door chain.
- Changing the lock type, i.e. if the lock is key-operated from inside, the carer/family may remove the key. However, please consider whether the person with dementia needs a Fire Safety Review and if they could follow a safe exit plan (See "Fire" section, p8).
- WLC's Support at Home Service to apply for a door exit sensor to alert the carer/family if the person with dementia leaves the house after a certain time of night for example.
- WLC's Occupational Therapy Service for a road safety assessment and possible provision of a GPS device (internet/phone based system to assist location of a vulnerable person when lost).
- Consider painting the indoor side of the front/back door to help it blend into the background so it is not easily visible (NB: see "Fire" section, p8).

Access inside your home: Hallway/Stairways

- Is the person with dementia able to go up/down stairs safely?
- Are there light switches at the top and bottom of the stairs?
- Are there banister handrails on both sides of the stairs?
- Does the person with dementia get confused due to the number of doors off the hallway?



Consider... (in no particular order)

- Improving lighting, e.g. install additional light switches, perhaps in a contrasting colour to the wall. Help may be available via Care & Repair's Small Repairs Service.
- Install additional banisters/grabrails via WLC's Self Selection Service.
- WLC's Occupational Therapy Service for assessment.
- Consider a carpet without patterns; is the tread worn; are there any tripping hazards?
- Consider use of pictures as signs on internal doors; contrasting colours; photos (e.g. images of the room behind the door).
- Consult "10 Helpful Hints for Dementia Design at Home" booklet by the University of Stirling.

Access inside your home: Living Room

- Difficulties operating various electrical appliances safely?
- Are the TV, radio, and computer easily accessible?
- Concerns about operating the gas or electric fire safely?
- Is there any fire risk?
- Is there a telephone near the armchair?
- Are there any tripping hazards, e.g. trailing cables, rugs?



Consider... *(in no particular order)*

- Reorganising layout / position of furniture.
- Removing tripping hazards.
- Care & Repair's Small Repairs Service may be able to assist with minor adjustments to household / furniture.
- Isolating any dangerous appliances, i.e. removing plug/fused spur. The Small Repairs Service may also be able to assist with this.
- Home Fire Safety Visit - contact your local Fire Station. Telephone 0800 0731 999 or visit www.firescotland.gov.uk.

Access inside your home: Kitchen

- **Is the person with dementia eating properly?**
- **Does the person with dementia know where to find things in the kitchen?**
- **Is the fridge well stocked? Is the food out of date?**
- **What type of cooker / fuel is used and are there concerns about operating it safely and/or independently?**
- **Are hazardous products stored safely, e.g. matches, sharp knives, scissors, bleach?**

Consider... *(in no particular order)*

- Prompt/encourage the person to eat; try to have protected mealtimes and keep them calm/quiet; a food diary can identify likes/dislikes/eating patterns.
- "Eating well with Dementia – A Carer's Guide": a practical eating and drinking guide.
- Refer to GP (for onward referral to Dietician and/or Speech & Language Therapist) if the person is gaining/losing weight or has problems swallowing.
- Specialist plates; adapted cutlery; non-slip mat; two-handled cups via the OT Self Selection Service.
- The Dementia Circle project (funded by Alzheimer Scotland): information about everyday products that can help people with dementia stay independent for longer. Visit www.dementiacircle.co.uk.
- WLC's Support at Home Service for a telecare assessment, including a Home Safety Alarm, extreme temperature sensor (can be fitted above the cooker) and flood sensors.
- Review cooking habits: use microwave; electric instead of gas; or disconnect/isolate cooker. NB: the activity of preparing meals may be an important role, which can often be adapted to reduce risks.
- Use of a loud kitchen timer to alert the person when food is ready.
- Picture signage on appliances/doors; glass cupboard doors/removal of doors to show the contents; a communication board/book where reminders and notes can be left.
- Reorganise / de-clutter so that items most often used are the most easily accessible.
- Speak with family/visitors - what have they observed?; can someone be designated to check food 'use by' dates regularly?
- Consider delivery of frozen ready meals. NB: can be offered by the Apetito service via Social Work Referral.
- Is the person with dementia getting their own shopping? Consider local shopping services.
- Consider a cupboard lock or safe box to ensure hazardous items are safely stored.

Access inside your home: Bathroom

- **Can the person with dementia easily find the bathroom?**
- **Are you experiencing difficulties helping the person with dementia to get washed, dressed and/or shaved?**
- **Can the person with dementia manage their oral hygiene independently?**
- **Can the person with dementia safely use bathroom facilities, e.g. rise from the WC; get in/out of the bath?**
- **Is the person with dementia having toileting accidents or struggling to get in/out of the bath?**
- **Are the hot water taps / shower spray thermostatically controlled?**
- **Does the person with dementia leave taps running and plugs in?**
- **Does the medicine cabinet contain anything that could be hazardous? (including over the counter medicines)**
- **Are cleaning products kept in the bathroom?**

Consider... *(in no particular order)*

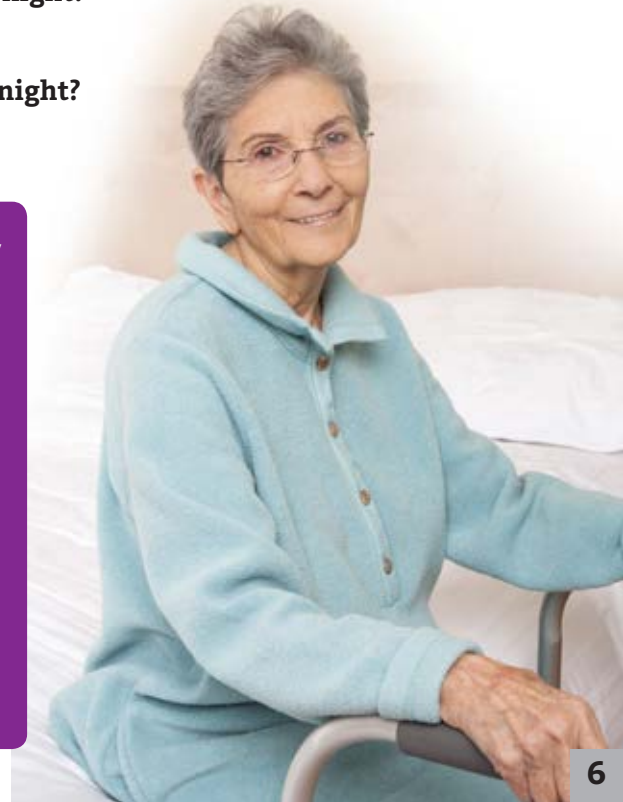
- Private purchase of a night light for use in the hall outside the bathroom and/ or leave the bathroom light on so it can be easily found.
- The Support at Home Service can provide a sensor to alert the carer when the person gets out of bed or link the sensor to a bedside light.
- Occupational Therapy Service for assessment of bathing/toileting equipment (e.g. shower board, raised toilet seat). Using a toilet seat/grabrails/ etc in a contrasting colour can be useful for people with dementia who can experience changes to their vision and may misinterpret their environment.
- Dentistry Service to The Oral Health Improvement Team, The Comely Bank Centre, 13 Crewe Road South, Edinburgh, EH4 2LD.
- When getting dressed, allow plenty of time for the task; encourage the person to sit down; suggest loose fitting clothing (e.g. elasticated waistbands and Velcro fastening shoes); lay out clothing in order with undergarments on top; ensure soiled clothing is put into laundry basket to avoid confusion.
- WLC's Self Selection Service for grabrails.
- Speak to your District Nurse (at your local Health Centre) about provision of a commode for use overnight and/or a continence assessment, e.g. if continence pads are no longer working, men may be able to use a continence sheath overnight. Also consider use of bed pads or waterproof sheets (private purchase) and community laundry (referral by District Nurse).
- Private Purchase of non-slip mat.
- Removing plugs from sink and/or bath to avoid flooding and flood/ temperature sensors for use when filling the bath (private purchase).
- Lockable medicine cabinet (Private purchase) and lock cleaning products away elsewhere.
- Electric razor used with a mirror outside the bathroom to avoid water contact.

Access inside your home: Bedrooms

- Does the person with dementia have problems sleeping and/or get up during the night?
- Is there a bedside lamp or torch within easy reach at night?
- Is there a ceiling light switch that can be easily reached during the night?
- If a walking aid is used is it next to the bed?
- Does the person with dementia have episodes of incontinence overnight?

Consider... *(in no particular order)*

- WLC's Support at Home Service: for a sensor linking the bedside light to a bed occupancy sensor; or an enuresis sensor (detects liquid). Alerts can go to West Lothian Careline or a carer and/or family member directly via a vibrating pillow alert or a pager.
- WLC's Occupational Therapy Service for assessment and equipment provision.
- Private purchase of a bedside lamp; touch-operated lamp; torch; baby monitor (to allow another household member to hear when the person gets out of bed).
- If the person with dementia has problems sleeping, are they stimulated enough during the day? Consider whether a family member/befriender could go for a walk with them. Could they attend a local lunch club, Dementia Café or a daycare service? Please see Alzheimer Scotland's website (www.alzscot.org) for a list of local resources or contact the Social Work Department for further information on 01506 776700.
- Refer to GP regarding sleeping problems.
- Refer to your District Nurse for provision of a commode and/or a continence assessment.



Falls/trip hazards

- **Is the furniture arranged to allow easy movement in/out of rooms?**
- **Is the floor free of clutter, trailing cables and scatter rugs?**
- **Is the room well lit?**
- **Does the person with dementia use a walking aid and are they still able to use it safely?**
- **Is the carpet secure & in good condition?**
- **Is the carpet free of busy/contrasting patterns?**
- **If glasses are worn, does the person with dementia have regular eye tests; are their glasses kept clean?**
- **What footwear does the person with dementia usually wear?**
- **Is the person with dementia able to manage their foot care, e.g. cut toenails?**
- **Does the person with dementia take a variety of different medications or medications with detrimental side effects?**
- **Is the person with dementia physically active?**

Consider... *(in no particular order)*

- Removing obstacles/trailing cables, and mopping up spillages straight away.
- Replacement of floor coverings - private purchase.
- Installing additional lighting/lamps. The Small Repairs Service may be able to help with installing extra ceiling lights.
- Regular eye tests – some Opticians offer home visits.
- Refer to Physiotherapy for (re)assessment of walking aids via your local Health Centre.
- Footwear - high heels, floppy slippers, shoes with slick soles and walking in your stocking feet can cause slips, stumbles and falls. Instead wear properly fitting, sturdy shoes with nonskid soles.
- Refer to the GP or the Community Pharmacist (based at St John's Hospital) for a review of medication.
- Refer to the Community Podiatrist Service for general information on 01506 523180 (please note that a regular nail-cutting service is NOT available).
- Doing regular exercises to improve strength and balance can help reduce the risk of falls. This can range from walking and dancing to tai chi classes or specialist training programmes. Ask your GP about training programmes in your area.

Fire

- Are there **WORKING** smoke detectors in the house?
Who checks the batteries or are they mains powered?
Are they fitted in the right place(s)?
- Does the person with dementia wear a hearing aid and is it working?
- Has the person with dementia had a recent fire safety check?
- Can the person with dementia safely exit the house in an emergency?
- Does the person with dementia smoke?



Consider... *(in no particular order)*

- Referral to the Fire Service for Home Fire Safety Visit for a fire exit plan and a free smoke alarm if required.
- Nominate a person to check the smoke alarms at regular intervals and replace batteries if necessary.
- See the GP for a referral to Audiology for a hearing test. Ensure the person with dementia has a supply of batteries and the hearing aid is regularly cleaned and tubing replaced.
- Refer to Deaf Action for a possible vibrating pillow alert linked to the smoke alarm. Other items also available include a flashing light doorbell; TV loop; and a pager to alert the wearer to the doorbell, phone and smoke alarm.
- Use deep, sturdy ashtrays (that don't tip over easily and will allow a lit cigarette to fall into it). Place ashtrays near the person with dementia but away from combustible materials and on a flat sturdy base (i.e. not the arm of a chair or the person's lap). Ensure cigarettes are out by placing a small amount of water in the bottom of ashtrays. Dissuade the person with dementia from smoking in bed. Encourage the person to smoke outside if this is safe for them. NEVER smoke near oxygen.

Garden



- Are there any problems with the condition of garden paths or widths (particularly if the person with dementia uses a walking aid)?
- Are steps and/or handrails needed to help access to the garden?
- Is the garden well kept?
- Is the person with dementia interested in gardening/able to continue maintenance?
- Is the perimeter of the garden safe / secure?

Consider... *(in no particular order)*

- The Small Repairs Service for possible help with altering paths and/or fences
- WLC's Occupational Therapy Service for assessment.
- WLC's Garden Maintenance Scheme (for grass & hedge cutting) if criteria met. There may be a charge for this service if you are not in receipt of a means-tested benefit.
- Local gardening volunteers, e.g. the Garden Angels Project.
- A befriender can help the person with dementia carry out meaningful activity. Check Alzheimer Scotland's website (for a list of local resources or contact the Social Work Department for further information.
- Creating raised flower beds and/or a circular walking route around the garden can allow the person with dementia to continue with an activity they always enjoyed and provide a way of getting exercise.

Routines / Patterns

- **Is it certain how the person with dementia manages when home alone?**
- **Is there evidence (rather than verbal reports) that they are not coping?**
- **Do you know if the person with dementia is taking their medication properly?**
- **Are they eating/drinking regularly?**

Consider... *(in no particular order)*

- Refer to WLC's Support at Home Service for possible use of a "Just Checking" system to assess the person with dementia's lifestyle patterns. This is a set of removable sensors placed at doorways to monitor movement around, as well as in and out of the home, 24hrs a day over a set period. This system is mainly used to determine if someone is getting up overnight multiple times, what room they spend most of their time in and if they are leaving the house at odd times of the day/night.
- Routines are very important for someone with dementia and the earlier good routines can be set up, the more likely these routines are to stay with the person as their condition progresses.
- Medication prompts via the Support at Home Lifeline or carousel dispenser.
- Private purchase of a dosette box (box split into sections according to the days of the week and time of day). NB: Ensure a note of all medications taken is attached to the dosette box – this is useful if the person is admitted to hospital.
- Speak to the GP about the possibility of the chemist dispensing medication in a dosette or blister pack and/or having medication delivered.
- Speak to the GP about the timing of medication, i.e. it may be possible for all medication to be taken at the same time of day.
- Leave a jug of water/flask of tea/sandwich easily accessible; etc.
- Social Work referral for a possible care package to prompt meals.



Behaviour

- **Does the person with dementia display repetitive behaviour: shouting/screaming; restlessness; aggressiveness; lack of inhibition; night time waking; following someone around; hiding and losing things; suspiciousness and paranoia; sleeplessness and “sundowning”?** (some people with dementia can experience increased periods of confusion at dusk.)
- **Is the carer/family member stressed as a result?** (See “Carer Support”, p13)
- **Is the person with dementia aware / concerned?**
- **Are there risks to the person with dementia or other due to any of these behaviours? Indoors and/or outdoors?**
- **Does the person with dementia have a formal diagnosis?**

Consider... *(in no particular order)*

- Try to remember that the person with dementia is not deliberately trying to be awkward but may be trying to communicate something. See Alzheimer Scotland’s website for advice on how best to respond to this behaviour.
- Support at Home Service for possible use of “Just Checking” for assessment of lifestyle patterns and/or provision of the Home Safety Service/sensors.
- WLC’s Social Work Service to assess for someone to be with the person with dementia to allow the carer/family member some time to themselves.
- WLC’s Occupational Therapy Service for a Safer Walking assessment.
- Consult the ‘10 Helpful Hints for Carers’ booklet by the University of Stirling.
- Liaise with other family members to spread the caring tasks.
- Contact the GP regarding a diagnosis to rule out other causes of unusual behaviour (e.g. urine infection). Depending on the possible causes of the dementia, the person may be referred to the Memory Clinic (held at St John’s Hospital) for assessment and/or a CT scan.
- Once a diagnosis is given, the person is entitled to a year’s post-diagnostic support. You can ask your GP to refer you for this service or contact Alzheimer Scotland for the Dementia Link Worker in your area. There is also medication that may be beneficial in some circumstances in treating the symptoms of Alzheimer’s disease.
- WLC’s Dementia Home Support Service provides initial short term support at home in order to allow an individual to build on their skills and abilities, and in doing so remain as independent as possible. This is aimed at people who have a recent diagnosis.
- There are personalised support services, dementia cafés and community resources available to support both the person with dementia and their family/carer. Contact Carers of West Lothian and/or Alzheimer Scotland for further information on this and many other issues surrounding dementia.

Legal Issues

- **Have you considered how to manage the person with dementia's finances?**
- **Are you concerned about the person with dementia's future ability to remain at home?**
- **Has a Power of Attorney been registered / invoked?**

Consider... *(in no particular order)*

- Joint bank accounts.
- WLC's Social Work Department for advice.
- Speak to your solicitor about Living Wills and/or an Advanced Statement, or telephone Alzheimer Scotland.
- Contact Carers of West Lothian. They offer support to carers (in groups or on the phone) and can access a solicitor service to provide Power of Attorney at a reduced cost. Please note that Power of Attorney forms can also be accessed on the internet and may be useful if the situation is straight-forward. However, they will still need to be registered with the Office of the Public Guardian, for which there is a charge.
- The Office of the Public Guardian (Scotland) registers Powers of Attorney and Welfare and Financial Guardianships.



Carer Support

- **A carer is a person of any age who provides unpaid care and support to a spouse, partner, relative, friend or neighbour, who cannot manage to live independently without the carer's help.**
- **Is the carer displaying signs of strain, e.g. pressure of speech, tearful, general appearance, etc.**



Consider... *(in no particular order)*

- Refer to WLC's Social Work Department for a Carer's Assessment.
- Support from Carers of West Lothian who will provide a free Carers Information Booklet giving a comprehensive guide to services in West Lothian. A carer support worker will also contact you to find out what kind of practical or emotional support you may need.
- Alzheimer Scotland's 24hr Dementia Helpline.
- National Dementia Carers Action Network (NDCAN) - a national campaigning network whose members have personal experience of caring for a person with dementia. Contact Alzheimer Scotland.
- Sitter services – either directly with the provider by private arrangement or via a Social Work referral.
- Contact Silver Line Scotland 0800 4708090 for information, friendship and advice (run by Age Scotland).
- A Package of Care – available from private home care agencies direct, or via Social Work referral (including provision of Self Directed Support if you wish to manage the care package independently).
- Respite – available via private facilities direct, or via a Social Work referral.
- The Answer Project offers a daycare service and Dementia Cafés. Practical help from other voluntary and statutory services such as shopping and meal delivery services; cleaners (private purchase).
- Keep in contact with other carers you meet, whether in person or by phone, or even via Skype on the internet.
- Over the Fence (a project funded by the Scottish Government) – a website containing independent information about how to access care and support.
- MECOPP (Minority Ethnic Carers of Older People) Carers Centre.

General

- **Is the house where the person with dementia lives adequately heated?**
- **Are there communication issues?**

Consider... *(in no particular order)*

- Can a designated person ensure the heating is turned on when needed and ensure that gas appliances are serviced yearly?
- Do the central heating controls need to be boxed in to avoid the person with dementia switching the heating off or altering the timings (controls would obviously still need to be accessible by someone). Alternatively, some energy suppliers can provide an App for your smart phone to control the central heating.
- Does the energy supplier have a scheme for people with disabilities, e.g. free gas appliance safety checks?
- Energy efficiency advice is available from some suppliers or contact the Energy Savings Trust. They can advise on home insulation and grants towards replacing some boilers.
- Age Concern provide information about home energy saving, help with benefits and using health services, as well as providing home and travel insurance (no upper age limit and you can cover your pre-existing medical conditions wherever possible). Carbon monoxide detector installation (possible provision from WLC's Support at Home Service or private purchase).
- Aids to communication include photographs, picture signage and/or verbal prompts, Talking Mats.
- Be aware of your non-verbal signals, make eye contact, speak clearly in simple sentences, be calm and unhurried.



In your Local Community

- **Does the person with dementia have difficulties walking over distances outside?**
- **Does the person with dementia need to access public toilets?**
- **Does the person with dementia have a lack of social outlets? It is known that keeping occupied and stimulated can improve the quality of life of the person with dementia, as well as for those around them.**



Consider... (in no particular order)

- Apply to WLC for the Taxi Card Service (reduced rates); or the Blue Badge Scheme (for people with physical disabilities).
- Dial-a-Ride (for elderly or disabled people living in West Lothian who have difficulty using ordinary buses).
- Lothian Shopmobility at Almondvale Boulevard, Livingston
- British Red Cross offer wheelchair loans, transport and escort, first aid training, international message and tracing, emergency response and therapeutic care.
- Refer to GP for Physiotherapy assessment of walking aids.
- Disabled toilets are available in most high streets and radar keys are available from Capability Scotland at the Ability Centre, Livingston. Alternatively, the Bladder and Bowel Foundation can provide a 'Just Can't Wait' toilet card.
- Discuss with the person what their hobbies and interests are. Try visiting the Living it Up website on <https://portal.livingitup.org.uk/location/lothian> for local activities.

Contacts

Age UK

Tel: **0845 833 0758** or visit
www.ageuk.org.uk/scotland

Alzheimer Scotland

Tel: **0808 808 3000**
or visit www.alzscot.org
24hr Dementia Helpline on
0808 808 3000

Answer Project

Tel: **01501 749974**
or visit www.answer-project.com

The Bladder and Bowel Foundation

Tel: **01536 533 255**
or visit
www.bladderandbowelfoundation.org/just-cant-wait-toliet-card

British Red Cross

Unit 1B, Bathgate Business Park,
Inchmuir Rd, Whitehill Industrial
Estate, Bathgate, EH48 2EP.
Tel: **01506 650754**

Capability Scotland's Advice & Support Service

Ability Centre, Carmondean,
Livingston EH54 8PT
Tel: **01506 674955**

Care & Repair's Small Repairs Service

Tel: **01506 424148**

Carers of West Lothian

Tel: **01506 448000** or visit
www.carers-westlothian.com

Community Pharmacist

St John's Hospital, Howden Rd West,
Livingston, West Lothian EH54 6PP
Tel: **01506 523000**

Deaf Action

Tel: **0131 556 3128**
or visit www.deafaction.org

Dementia Circle

visit www.dementiacircle.co.uk

Dial-a-Ride

Tel: **01506 633953**
or visit www.handicabs.org.uk

Energy Savings Trust

Tel: **0808 808 2282**
or visit www.energysavingtrust.org.uk/Scotland

Fire Scotland

Tel: **0800 0731 999**
or visit www.firescotland.gov.uk

Garden Angels Project

Tel: **01506 650111**
or visit www.vsgwl.org

Home Security Scheme and Garden Maintenance Scheme (WLC)

Tel: **01506 280000**

Leaflet "Eating well with Dementia – A Carer's Guide"

Download from
www.scot.gov.uk/Topics/Health/Services/Mental-Health/Dementia

Living it Up

A web-based service to help you
get and share information for a
healthier lifestyle.
Visit <https://portal.livingitup.org.uk>

Local shopping services

e.g. **The Food Train**
Tel: **01506 413013**

Lothian Shophmobility

Tel: **01506 442744**

MECOPP (Minority Ethnic Carers of Older People) Carers Centre

Tel: **0131 467 2994**
email info@mecopp.org.uk
or visit www.mecopp.org.uk

Occupational Therapy Self Selection Service (WLC)

Tel: **01506 775666**
or visit www.westlothian.gov.uk

Occupational Therapy Service (WLC)

Tel: **01506 775666**

Over the Fence

Visit www.overthefence.org.uk

Office of the Public Guardian

Tel: **01324 678300**
or visit www.publicguardian-scotland.gov.uk

Social Work Referral

Tel: **01506 776700**

Support at Home Service (WLC)

Tel: **01506 775651**

Taxi Card Service and the Blue Badge Scheme

Tel: **01506 280000**

The Silver Line

Free helpline providing
information, friendship & advice
to older people.
Tel: **0800 4 70 80 90**

University of Stirling

Tel: **01786 467740** or visit
www.dementia@stir.ac.uk

West Lothian Careline

Monitor telecare equipment 24
hours a day.
Tel: **01506 414871**

West Lothian Council Occupational Therapy Service

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West Lothian

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Information is available in braille, tape, large print and community languages.

Contact the interpretation and translation service on **01506 280000**.

Text phones offer the opportunity for people with a hearing impairment to access the council.
The text phone number is **01506 591652**. A loop system is also available in all offices.

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