

PROVISION FOR PEOPLE WITH DEMENTIA

Both KEY and Community Lifestyles have considerable experience in delivering high quality support to help people who have developed dementia to continue to live fulfilled lives in the community.

Some people with dementia have been supported by us for many years prior to the onset of their illness. In addition we are sometimes approached to provide new support services to people who are already living with dementia. Sometimes this is because the person has a learning disability and we are recognised as having long experience of supporting people with learning disabilities with additional complex needs. In other situations we are approached, not because the person has a learning disability but simply because the person's family or care manager feels that they will benefit from the person centred and highly individualised support services we offer.

In all situations we are committed to working with the person who requires support and alongside those who are closest to them to ensure people have the best possible quality of life, maintain and develop activities and relationships that are important to them and exercise as much choice as possible.

Our approach to providing support to people with dementia is completely aligned with **Scotland's National Dementia Strategy: 2013-16** which outlines the following standards.

- The right to be regarded as a unique individual and to be treated with dignity and respect.
- The right to a diagnosis
- The right to access a range of treatment and supports.
- The right to be as independent as possible and be included in the person's community.
- The right to have carers who are well supported and educated about the person's illness
- The right to end of life care that respects the person's wishes.

It is also aligned with the **Charter of Rights for People with Dementia and their Carers in Scotland**

Our Experience of Supporting People with Dementia

KEY and Community Lifestyles currently support over 1600 people of whom approximately 50 are diagnosed with dementia. Most of these people live in their own homes in a wide variety of locations

throughout Scotland. In a small number of situations we also provide family support to individuals with learning disabilities who are living in the family home with a parent who has dementia. In such situations we strive to meet the individual needs of all parties as well supporting the family unit.

The number of people we support with dementia is steadily increasing, partly because of the age profile of the people we currently support and partly because of the higher incidence of dementia within the population of people who have learning disabilities, particularly people with Down's Syndrome.

We anticipate that this trend will continue given our lifelong commitment to the people we currently support and our commitment to developing specific high quality support arrangements for people with dementia applying to KEY or Community Lifestyles for support.

How long have we been supporting people with dementia?

We have been supporting people with dementia since KEY was set up over 30 years ago and have been supporting some people for over 10 years since their diagnosis.

We are deeply committed to supporting people for as long as possible in their own home, where ever this is their wish (or that of their families or representatives if they are unable to express a view).

Inevitably this means that we sometimes provide end of life care. In these situations we work very closely with both community health and palliative care teams.

We have an excellent reputation for sticking with people through both the good and not so good times in life and we have a total commitment to providing flexible services that can adapt to changing needs during the course of the person's life.

Our success in this area is due to the quality of relationships that are fostered between our staff and the people they support. These genuinely caring and respectful relationships are such that our staff are invariably willing to go the 'extra mile' to continue to support the person at home if this is possible.

In the small number of situations where people have moved into nursing homes, this has been a difficult decision arrived at because of complex health issues which have lead to multiagency and family agreement that such a move was in the person's best interest.

Who are the people with dementia that we support?

We support equal numbers of men and women with dementia and their age range is from mid thirties to early eighties.

70% of the people we support with dementia are tenants in their own home living alone or in small shared accommodation. A few people remain in their family home and a very small number are living in residential care with additional support provided by KEY or Community Lifestyles

Approximately 35% of the people we support with dementia also have Down's Syndrome.

Our approach to supporting people with dementia

Our main aim is to support people with dementia in a respectful and dignified way to lead fulfilled lives for as long as they are able to, while ensuring their safety and protecting them from harm.

We strive to provide each person with just the right amount of targeted individual support to maximise their independence and to complement the support available to them from other sources. We provide a very wide range of support including all aspects of personal and home care as well as community and social support to help the person enjoy a fulfilling and engaged lifestyle. The amount of support that people receive depends on their specific needs and circumstances. In some situations we provide only a few hours support per week and in others we support the person at all times. Some people also have night time support in their house or assistive technology to alert sleepover staff if they require assistance during the night.

For people with dementia, we recognise the critical importance of maintaining strong links with family, friends and of finding creative ways of keeping the person engaged with the activities and interests that they enjoyed prior to the onset of their illness. Above all our support is flexible and continually adapts to meet the changing needs of people throughout their life.

“I am very pleased with the support to my sister, I couldn’t wish for a better place, I feel my life is made easier knowing that my sister is living here and have no worries. Workers are more like family than carers”

Quote from supported person’s brother

Because people with learning disabilities and particularly people with Down's Syndrome are more susceptible to dementia we seek to ensure that where necessary an early diagnosis is sought to ensure that people receive appropriate and informed support. Current good practice guidance suggests that people with Down’s Syndrome should have a baseline assessment at age 35 and other people with learning disabilities at age 60.

In addition to our housing support and care at home, KEY and Community Lifestyles also provide short break services which can offer additional support to individuals as well as providing families with a break from caring responsibilities. This support is usually offered in the person's own home although in a few areas we do have designated short break accommodation. Also where appropriate and not too disorientating for the individual, we can offer short breaks in holiday accommodation

When providing short breaks we pay close attention to the fine detail of people's support requirements to ensure that the individual and their family can benefit from the break without difficulties arising from changes to routines and living patterns that are important to the person's wellbeing.

Service Principles

Our Support Services for people with dementia are designed in line with the following service principles.

- Understanding and respecting the challenges faced by the individual with dementia and their family; responding at all times with empathy, kindness, patience and consistency.
- Enabling each individual to maintain a good quality of life and make the very most of each day, while ensuring their safety and well being in situations where they may be vulnerable.
- Using a person centred approach to support the individual on their dementia journey with a total commitment to adapting and amending arrangements to suit their changing requirements.

- Ensuring close partnership with families to make sure we have as much information about the person's history, preferences and lifestyle prior to the onset of dementia.
- Ensuring that outcome based support plans reflect the unique characteristics of the individual and how their dementia impacts on them. For example, plans will detail what the person's diagnosis is; what their routines are; special interests/skills; effective communication and what needs to be in place to help the person cope with the challenges of everyday life.
- Understanding that all behaviour is a form of communication and managing and responding to complex and challenging situations positively and creatively when they arise.
- Supporting the individual to remain within their home for as long as wherever possible and where this is in line with the person and their families wishes.
- Where it is required supporting an individual and their family/carers in end of life planning in accordance with expressed wishes and preferences.

Outcome Focused Planning

Our approach to service design and support planning for people with dementia derives directly from our approach to personalisation. We have a deep commitment to ensuring that every individual support arrangement is designed to meet the person's unique requirements and to help them achieve their personal outcomes, support is delivered by a small team of staff who know and understand the person well.

We use a range of person centred planning tools and accessible recording systems which are structured around the specific needs of the person being supported. These tools provide a basis for regularly reviewing support arrangements and ensuring that their support is consistently delivering desired outcomes for the individual and maximising their independence whilst ensuring their safety and wellbeing.

"Workers do everything they can to support M to remain in her own flat and continue to support her to have and enjoy a good quality of life."

Quote from M's advocate

Partnership Working

High quality community services for people with dementia require a multi-agency approach and we work with a wide variety of partner agencies to deliver joined up services.

This ensures both quality supports for the people with dementia and also appropriate advice and guidance for their support teams and families. Examples of this are:

- Community Nursing and GP services – help us respond to the health care needs of the people we support.
- Psychology and Psychiatry –provide assessment and additional specialist support to people whose dementia leads to complex behavioural patterns or emotional confusion.

- Speech and Language Therapy where appropriate can provide essential support in determining the communication systems will be most appropriate for each person.
- Social Work – provide care management services and their input is central to ensuring that the person’s support reflects their full range of needs and is funded accordingly.

Working in partnership with these agencies we have a reputation for working effectively, creatively and in a consistently solution focused manner.

Staff Training and Support

KEY and Community Lifestyles ensures that every worker who is supporting someone with dementia receives the necessary training to enable them to provide high quality person centred dementia specific support.

Induction

All new staff undertake a structured induction programme which starts with an input from a person (co trainer) who uses our support services. This serves to demonstrate KEY and Community Lifestyles commitment to listening closely to the perspectives of people we support and stresses the importance of participation and involvement.

‘It’s really important that workers hear from the people who receive support as part of their training. We are the experts, we are the people who know what good support and bad support is. For me to have the life I want, I need my workers to be the best they can.’

Quote from Co-trainer

The induction course cover the essential elements of outcome focussed person-centred support; as well as covering SSSC Codes of Practice; effective communication; understanding behaviour; moving and handling and emergency aid.

Dementia Specific Training

Following on from induction our dementia specific training helps staff to blend a theoretical understanding of dementia with detailed knowledge of the person they are supporting so that they can confidently deliver highly individualised support in a dementia friendly way.

Our learning and training approach reflects the National Dementia Framework: Promoting Excellence and relates to two levels: Dementia Informed and Dementia Skilled.

All staff working with people who are at risk of developing dementia are trained to be ‘Dementia Informed’ In addition, where staff are supporting a person who has a suspected or confirmed diagnosis of dementia they are trained to be ‘Dementia Skilled’

This understanding is then combined with learning from a detailed outcome-focused planning approach which is asset based and builds on the person’s strengths and gifts. This enables staff to develop an

understanding of important aspects of someone's life and, how that person needs to be supported in relation to their dementia

This approach enables our staff to understand the specific ways in which the dementia affects the person's cognitive skills and behaviour and then deliver support in a way that is most appropriate to the individual

Commitment to partnership working is reflected in all our training and where relevant input is provided by colleagues from other agencies who have specialist knowledge and spend time with support teams to resolve person specific issues in relation to dementia. They also provide guidance to staff teams to help resolve specific issues.

“Through out my time of assessment with the lady in question I was very impressed with the standard of care being delivered and the knowledge base and skills of all support workers in the ladies team “

Quote from Clinical Psychologist working with a lady who has Dementia

Where possible and appropriate family members also contribute to team training. This provides staff with the opportunity to learn from the expertise, knowledge and unique insight that the family have of their loved ones life history, interests and preferences.

This learning is enhanced by other training opportunities in a wide range of related topics e.g. epilepsy awareness, assistive technologies and intensive interaction.

Behavioural Support Training

When someone has dementia there can be significant changes in the manner in which they behave and express their wishes. Understanding these new behaviours and the communication intent behind them can be a challenge for the person's family and carers.

KEY and Community Lifestyles have a team of qualified behavioural specialists who are accredited as Behavioural Support Strategy (BSS) Instructors, by the British Institute of Learning Disabilities and who deliver training tailored to individual needs and circumstances.

The BSS course equips support teams with the understanding that all behaviour is a form of communication and helps them develop a range of strategies that will help them manage situations and the environment to avoid distress for the person and minimise the risk of the concerning behaviours arising.

This training has a particular focus on communication, need for consistency of support, environmental and sensory issues.

Following this training, the support team develop a Dementia Intervention Support Plan for the person. This document, which is reviewed regularly, clearly lays out the expectations of the worker team as to how they will support the person, identifies triggers which may cause the person anxiety or distress and then offers strategies as to how best to avoid these situations occurring.

"The training gave me an insight into how someone with dementia sees the world. The training was directly linked to the man I was supporting- it helped me understand the changes that he is going through due to his dementia."

Quote from course participant

Continuously improving our services for people with Dementia

KEY and Community Lifestyles are committed to continuously improving our services to people with dementia.

Individual services are reviewed regularly with all stakeholders encouraged to comment on the quality of the service and share any ideas for improvement. These comments are fed through into the reviewing process for both Outcome based Support Plans and Dementia Intervention Support Plan.

We also undertake regular training audits in our services to ensure that training is comprehensive and up to date.

In addition KEY and Community Lifestyles have a Community of Practice where a group of experienced managers can share experience and expertise. These discussions feed through into our staff and policy development agendas.

All our services, including those where we support people with dementia, are inspected by the Care Inspectorate and consistently achieve very good and excellent grades (5s and 6s).

Service Leadership and Robust Backup

In designing and delivering services for people with dementia we recognise the need for strong leadership and for competent and confident services managers.

All managers are trained to lead and deliver outcome focused support services and are committed to leading with a style of staff management, support and supervision that supports this approach.

Staffs at all levels are provided with regular, formal 1:1 supervision and appraisal. This is backed up by management structures that enable immediate and responsive supports as required.

Good teamwork and peer support are viewed as essential components of providing a quality service and this is fostered through regular team meetings which are usually led by a team leader or more senior manager.

KEY and Community Lifestyles Staff Development and Training Officers attend team meetings as required and meetings are often further enhanced by contribution from external professionals.

The Right Accommodation

Most people we support with dementia live in their own tenancy, sometimes living with a friend or partner. We recognise that for many people with dementia it is important to them to have a quiet, calm and familiar environment where they can safely exercise some control over their immediate surroundings

Our experience has demonstrated that the right accommodation along with appropriate assistive technologies and/or relatively small scale housing adaptations can be critical in helping people with dementia thrive in their community.

Key Housing Association provides property development services. This enables us to approach housing procurement, adaptation and management with an understanding of the particular needs of the people we support.

When choosing or adapting accommodation for people with dementia, we have found that it is essential to have an understanding of how individuals experience their environment and perceive people and objects within this environment.

A detailed environmental needs assessment is carried out in advance of any housing decisions being taken and helps us to design dementia friendly environments with appropriate lighting, acoustics, signage, access, ventilation and use of colour and materials to minimise sensory confusion and reduce anxiety. Providing environments in which the individual's strengths and special interests can be harnessed further enhances basic motivation and confidence,

For example protected and private garden space or quick and easy access to open public space such as parks or gardens can provide important outdoor space.

Around 40% of the people we currently support have specific housing adaptations: