# From the Race Equality Foundation website

# Supporting people living with dementia in the Jewish community



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There are approximately 270,000 Jews living in the UK.  There are numerous Jewish charities working with older people and people living with dementia including Jewish Care, Nightingale Hammerson, and Edinburgh House in London and the South East, Birmingham Jewish Community Care, The Fed in Manchester, and Leeds Jewish Welfare Board.  This article outlines the approach and experience of Jewish Care to supporting people living with dementia.  Jewish Care is a leading communal organisation.  It is the largest health and social care charity for the Jewish community in the UK, touching the lives of 10,000 people  every week with a wide range of services from youth clubs to residential nursing homes.  The organisation employs 1,300 staff from multi-cultural backgrounds together with 3,000 volunteers who help maintain our services.

Based on statistics from the 2011 census the Jewish population has a slightly higher median age than the general population being 41 years compared to 39 years.  Proportionately there are significantly more people over 80 and over 85 than the general population.  In 2011, 21% of the Jewish population in the UK were over 65.  Given that statistically the prevalence of dementia is greater as age advances and particularly for people over 80, clearly the Jewish community has a significant challenge to meet.

As in most communities, the Jewish community’s understanding and awareness of dementia has grown a great deal over the past twenty years.  In Jewish Care, we have embraced the shift in thinking on dementia care from a medicalised model where people with dementia were treated as patients to a model where their social, cognitive and psychological wellbeing is highlighted.  We have adopted what Kitwood (1997) described as the person-centred approach.  This is an approach that emphasises authentic contact and communication.  Kitwood  described person-centred care as ways of working that emphasise communication and relationships.  This way of working with and understanding people living with dementia has developed into the relationship focused approach.  The relationship focused approach recognises the importance of building and strengthening relationships and that this remains very important for people living with dementia.  As a community organisation, the relationship focused approach fits perfectly with the idea of belonging to the Jewish community and maintaining this identity.

In 2009 the government launched “Living well with dementia: A national strategy” in which it outlined a comprehensive range of initiatives to support people living with dementia from early stages of end of life.  In this organisation, we took the ethos of this strategy to develop our own Dementia Strategy for Jewish Care. The implementation of our strategy for dementia care was contained within a framework with the three main aims of the national strategy which we adapted.  Below, a summary of the strategy is outlined together with the progress we have made.

Strategic Aim 1: To raise a better understanding of dementia in the Jewish Community and address any misconceptions about the condition.

There was a general understanding of dementia within the Jewish community.  There was also a widespread mis-attribution of symptoms to “old age” and a resultant unwillingness by some people with dementia and their families to seek help.  This was also echoed within mainstream care provision, with a false view that there is little or nothing that can be done to assist people with dementia and their carers.  There also remains within society a real problem of stigma and fear associated with dementia which can delay early diagnosis and the accessing of good quality care.  This results in people with dementia and their carers/families becoming isolated from the Jewish community.  Better understanding of dementia leads to more integration of people with dementia and their carers in the Jewish community.

For the past twelve years we have worked with the local Jewish community through networks and going into synagogues and schools to promote a better understanding of dementia.  Since 2012 we have run Dementia Friends programmes run by our own Dementia Friends Champions.  We have also promoted the idea of the Jewish community becoming a Dementia Friendly community.  The awareness and understanding of dementia has grown significantly and Synagogues’ social welfare workers are shifting approaches to working with people living with dementia from a person-centred perspective.  This is ongoing work and requests for training and support come in regularly to Jewish Care from synagogues and other community groups.

Strategic Aim 2: Ensuring members of the Jewish community receive early diagnosis of dementia and access to support services.

In 2009 only a third of people with dementia received a formal diagnosis at any time in their illness.  When diagnoses were made, it was often too late for those affected by the condition to make choices.  Alternatively, diagnoses were often made at a time of crisis, a crisis that could have been avoided if diagnosis had been made earlier. Our strategic implementation in this area was therefore to concentrate on ensuring that people living with dementia and their family carers have access to effective services for early diagnosis and are guided to the most appropriate support from this point onwards.  Early diagnosis empowers people to participate in planning their own future.

Our organisation has a comprehensive pathway of support for people living with dementia and their carers.  Typically, the first point of contact is the Jewish Care Helpline which is a free service.  Helpline staff are trained to work with people with dementia and are knowledgeable about services available locally.  The helpline team will either refer a caller onto local services, either within Jewish Care or in the wider community, or if further support is required refer them to a member of Jewish Care’s Community Support and Social Work team who will then arrange to talk to them or meet them to discuss their specific needs further. If support is needed for the carer, a separate referral can be made to the Family Carers Team.  People are supported and guided on how to access support from the NHS and Local Authorities.  They will also be supported to find out more about Jewish Care’s dementia services and other organisations and charities.

The Community Support and Social Work (CSSW) team has a specialist dementia team.  This team has strong links with local and national services and can provide support in the community to those who are living with dementia.  The team also works closely with all Jewish Care’s services, especially those for people living with dementia, for example Memory Way Cafés.  Following on from the initial contact with the Help Desk a member of the CSSW team can call the person back.  They may also arrange a visit to have a more in-depth conversation.  The CSSW worker can remain in contact with the person for several weeks, months or longer.  Often a CSSW worker(s) will have worked with a person from early diagnosis to later stages when a person may seek further care (such as home care or residential care).  The service can work with very practical advice like how to apply for Lasting Power of Attorney (LPA) to the emotional aspects of living with dementia. This service is free.

The Family Carers Team are trained to work with carers of people living with dementia.  They are there to support and enable the family member to continue this vital role (if that is their wish).  They offer emotional support, practical advice and guidance, information and access to various services and advocate on their behalf to help ensure they receive any assistance to which they are entitled.  This is a free service.

Strategic Aim 3: Ensuring our service users receive consistently high-quality care from the onset of dementia to the end of life.

We are committed to enhancing the way we serve Jewish people with dementia and their families; ensuring they receive quality support that reflects emerging good practice and new ways of working. We committed to develop our workforce to achieve core skills and knowledge in dementia care, creating a pathway that ensures people with dementia and their carers receive culturally sensitive services that enable and involve them as partners in care at all stages of the condition.

Since 2012 Jewish Care has had a dedicated team to support staff development across the organisation in dementia care.  The team is the Arts, Disability and Dementia Team (ADDT).  Their learning and development strategy aims to develop core competencies as follows:

Relationship focused approach

We work to equip staff and volunteers to engage with the people using our services and to build relationships with them on an equal basis as people.  This involves good communication, empathy, active listening, being able to put yourself in the place of the other person, and building community (working collaboratively with the person and supporting that person to engage with their communities).  It encompasses an awareness of how to support and encourage the relationships between people (according to the individual’s wishes), creating opportunities for people to live and participate in, and to be enabled and empowered to contribute to communities.  This is the opposite of a task focused approach and involves a cultural shift from that way of working.

Resourcefulness and creativity

Working with staff and volunteers to be in tune within their own resourcefulness and have confidence within it.  In practice, this involves being confident to recognise and focus on the needs of the people using our services including mental health and wellbeing.  It means being able to use that creativity relating to the people who use our services, including building spontaneous opportunities for fun and bringing forth a meaningful life.  Jewish Care values the personality and caring nature of our staff and volunteers and the way that these characteristics can enhance the experience of the people who use our services.

Creativity is not only about taking part in arts activities, it is also about breaking away from the way things are usually done by using new approaches.  A participatory arts approach can be applied to a one-to-one session or a group and is facilitated rather than directed by the creative practitioner.  The facilitator takes the direction from the person with dementia, starting where they are.  The activity focuses on the person’s strengths, not on dementia or disability.  Choice for each participant is provided at a level suited to that individual.  Everyone’s contribution is valued.  Participation in the activity can be verbal or non-verbal, sensory or just observation.  It is during the process of an activity where meaningful connections are made and memory and creativity can be nourished and expressed.

Delivering an enabling culture of care

Working with staff and volunteers so that their approaches support and strengthen the abilities of our service users and reduce their limitations. They recognise that the person is at the heart of our care and they are driving their support services.We are empowering the person to achieve what they want and inspire them to reach their full potential.  Staff and volunteers seek to identify and understand what the person can do and work creatively to enhance this.  In this context, it is essential to be able to recognise and to have good strategies to respond to impairments such as sight loss, hearing loss and agnosia so that the person can still adapt and achieve what they would like to do.

Responding to psychological, emotional, cultural and spiritual needs

Staff are developed and supported to recognise that loneliness and isolation are often associated with conditions and disabilities.  They are equipped to address and respond to emotional and psychological needs and to see that these are as important as support with physical needs.  Sometimes this also involves reconciling individual needs with communal living and an understanding and ability to respond to the interpersonal and social nature of our environments.

Skills for reflective practice

Being with staff and volunteers on their journey of learning and professional development through reflective practice is crucial.  Relationship focused and person-centred care is a continuous learning journey as this approach is individual to each person.  Staff and volunteers will be supported through two elements of reflective practice; establishing and building upon good working practices to improve quality of life (this includes processes, standards and documentation).  We help to develop competencies that can be used in recruitment, appraisals and supervision.

Providing a comprehensive range of services for people living with dementia

We aim to support people living with dementia from pre-diagnosis to end of life through a range of high quality services within the context of Jewish cultural settings.  People usually have initial contact through the helpline and Community Support and Social Work (CSSW) teams (described above – Strategic Aim 1).  Other services offered by Jewish Care specifically for people living with dementia are:

Memory Way Cafes – Warm and welcoming environments for informal social gatherings for people living with dementia together with their family carers.

Singing for Memory – Singing sessions providing a stimulating social environment bringing together people who are living with dementia and their carers.

Day Centres for People Living with Dementia – Offering people living with dementia support in decision making and using their capacity for choice along with developing strategies to live with their dementia. All of our centres, services and homes celebrate Jewish festivals whether it be a Seder service, Purim show or Rosh Hashanah.  We also celebrate Jewish traditions such as Shabbat kiddush (prayers) and candle lighting.  This allows people to maintain their Jewish cultural heritage and so feel part of a warm community.

Home Care – Jewish Care’s Home Care service is designed to offer members of the Jewish community the support they require to live independently in their own home from staff who are trained to understand their culture and traditions.

Residential Care and Nursing Homes – We have care and nursing homes  that have been refurbished, redeveloped and/or purpose built to enhance the quality of life for people living with dementia using up-to-date dementia design principles.  Care and nursing staff receive ongoing dementia training.  We have a network of dementia training and the Arts, Disability and Dementia Team provide bespoke training and ongoing support and mentoring for best dementia practice.  Our staff are trained in end of life care and we work to ensure people can live well with dementia up to end of life and so die in a familiar Jewish environment.

Independent Living – Our independent living apartments offer rental housing with care from an on-site support team and aim to support people to live independently if/when they develop dementia.

Supporting people living with dementia and their spiritual lives

In Jewish Care we value the rights of people living with dementia to live their faith and cultural traditions.  Supporting people to live well with dementia often brings unexpected and surprising rewards.

Rabbi Cary Kozberg writes “Dementia may steal the mind but it cannot encroach upon the soul.  In my work I see how alive and vibrant the soul can remain, even when a person’s cognitive capacities are significantly diminished.  This is because G-d addresses each person in the way he or she is able to hear, as Midrash Tanhuma affirms: “The voice of the Eternal is in the strength-that is, fitted to the strength, the ability-of each and every person: men according to their abilities, women according to their abilities, and young according to their abilities, the elderly according to their abilities.” As I’ve learned…sometimes the soul can hear the Voice even better, and respond more spontaneously when the mind no longer gets in the way”.

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