

Harnessing community information and support  
for people with young onset dementia and their families:

# Guidance for community groups and healthcare professionals

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THE ALZHEIMER  
SOCIETY *of* IRELAND



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**If citing report, please reference it as follows:**

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This guidance document and research was commissioned by The Alzheimer Society of Ireland and was conducted in collaboration with key stakeholders including people with young onset dementia and their families.

# How to use this guidance document

This guidance document presents practical recommendations which may be utilised by community groups or healthcare professionals to consider the needs of people with young onset dementia under four central themes:

- 1: Awareness and training**

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- 2: Individualised and social supports tailored to the person's needs and preferences**

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- 3: Mapping and signposting of community supports**

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- 4: Making community supports more accessible for people with young onset dementia**

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Each section also contains a list of community-based supports which are currently available in communities and may be of benefit to people with young onset dementia and their families.

## Young Onset Dementia

Dementia is typically diagnosed in people over 65 years of age, but there is a growing awareness of the prevalence and impact of dementia diagnosed in people under the age of 65. This is referred to as 'young onset dementia'. A diagnosis of young onset dementia can have magnified challenges, as the person may be in active employment, have significant financial responsibilities, and have young families.

Much of the research evidence focusing on post-diagnostic supports for people with young onset dementia highlights the importance of the individual staying socially connected and engaged in meaningful, purposeful activities. However, mainstream dementia services are often designed to cater to the requirements of older people, meaning that supports are not always appropriate for a younger person with dementia.

**Note on terminology:** For the purposes of this document, the term services is used to describe formal health or dementia services. The term supports relates to a wide range of community-based activities and can be either structured or informal in nature, such as social support groups. Also discussed are a range of public-facing services, resources, and organisations (such as banks and transport providers) that are available in the community.



## Importance of the local community

People with young onset dementia can benefit from relevant and accessible support in their communities. For a person with young onset dementia, their needs for social and emotional support may be as important as their medical needs. People with young onset dementia express a preference for continuing their usual community-based activities. Taking small steps to optimise the social and lived environment of our communities is an ideal way to achieve inclusive, accessible, and relevant approaches for people with young onset dementia.

Currently, there are many examples of positive initiatives within our communities. There are, however, many potential areas for improvement.

- Firstly, there are ways that services, organisations and businesses (e.g., retail, transport providers) can enhance their environment and practices in order to become more aware and more inclusive of people with young onset dementia.
- Secondly, there are many innovative and relevant supports and resources already in operation in local communities (e.g., community support groups; legal and financial advice) which could be of benefit for people with young onset dementia and their families. It is important that these supports are open and accessible to people with young onset dementia.



# How this guidance document was developed

This guidance forms part of a larger project which explored ways in which to harness community supports for people with young onset dementia and families. This project consisted of a rapid review of the evidence base and focus groups with healthcare professionals, people working in community settings, people with young onset dementia and their families.

A draft summary of overall findings was shared with key stakeholders to gather feedback and establish consensus on areas of priority and focus. These areas of priority formed the basis for this guidance document. This report is available at [www.alzheimer.ie](http://www.alzheimer.ie)<sup>1</sup>

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1 Kilty, C., Curtin, C. & Fox, S. (2022). Harnessing community information and support for people with young onset dementia and their families. Available at [www.alzheimer.ie](http://www.alzheimer.ie)

## The four central themes:



### 1: Awareness and Training



### 2: Individualised Approaches & Social Approaches



### 3: Mapping and Signposting of Community Supports



### 4: Making community supports more accessible for people with young onset dementia

## Theme 1: Awareness and Training



People with young onset dementia are impacted by dementia at a time of life when they have significant societal, financial, employment and family-related responsibilities.

People with young onset dementia have reported a desire to remain actively involved in communities, and evidence suggests that there are helpful steps that can be taken to ensure communities and resources are inclusive.

People with young onset dementia often experience issues with cognition, memory, planning and communication. A key first step is to ensure that communities and organisations are aware of young onset dementia and of the challenges faced by people living with young onset dementia.

All sectors of the community should consider ways to implement practices that are inclusive of people with young onset dementia. The value and benefit of existing community supports for a person with young onset dementia can be enhanced through a wider public awareness of young onset dementia, along with knowledge of practical ways of supporting people with young onset dementia.

We can consider our community environments and adopt inclusive practices such as ensuring staff are aware and informed, and ensuring information and processes are clear. Training to improve awareness and understanding can enable the local community to support people with young onset dementia, and to implement dementia-friendly practices, minimising the challenge of geographic spread.



## 1. Awareness and Training

### Recommendations

#### Recommendations for formal services;

- Services should prepare training programs, or informational resource packages, to improve young onset dementia awareness, knowledge, and support amongst communities and organisations. This is of particular importance in the case of organisations that may regularly interact with people with young onset dementia.
- People with young onset dementia should be included in the delivery of training to make the training more effective and impactful.

#### Recommendations for community groups/organisations;

- ‘Dementia Champions’ training and initiatives should be considered within organisations and businesses that deal with adults, not just older adults. Dementia Champions can take on a leadership role within organisations, to share knowledge and drive change.
- In addition to training, community organisations should consider the integration of a dementia- inclusive ethos and/or policy, and should receive support from The Alzheimer Society of Ireland.  
and dementia care providers in this respect. Visual indicators should be used to highlight businesses which are (young onset) dementia-inclusive/aware. For example, the use of badges and signs for staff and businesses that have completed relevant training.
- Intergenerational initiatives should be considered. Schools and third level institutions should consider ways to raise awareness of young onset dementia.

### Relevant Resources

- Creating Dementia Friendly Communities – A Guide: [available here](#)
- Dementia friendly practices in Primary Care: [resource available here](#)
- WHO toolkit for dementia-friendly initiatives (DFIs): Towards a dementia-inclusive society: [available here](#)
- Dementia Champions – how to get involved: [available here](#)
- Dementia-inclusive communities in Ireland Webinar: [available here](#)
- Dementia Inclusive Community Guide from a Universal-Design-approach: [available here](#)
- Universal Design Walkability Audit Tool for Roads and Streets (National Transport Authority): [available here](#)
- Dementia Elevator Training for Businesses and Customer-Facing Services: [available here](#)
- ASI Charter of Rights for People with Dementia: [available here](#)

*This list is not intended to be exhaustive\**

## Theme 2: Individualised Approaches & Social Approaches



People with young onset dementia should be supported to maintain everyday life, interests and activities, and should be recognised as having varied and individual support needs and preferences.

Owing to differences in age and stage of life, people with young onset dementia have expressed a preference for supports outside of dementia-specific services.

It is important that healthcare professionals and people working in community settings are aware of these preferences and support people with young onset dementia to continue to engage in their preferred day to day activities. It is important to consider a person's strengths, abilities and preferences, and to remove barriers to participation.

Across communities, we can ensure our practices are inclusive and flexible, so that they may be more readily accessed by people with young onset dementia. Furthermore, we can use social models of support to harness existing supports in the community.

Healthcare professionals should be mindful that any pathway or model of support developed for people with young onset dementia should include local supports in the community. Social models of support such as social prescribing approaches, if utilised, have the ability to provide a wide range of relevant and responsive options within communities.

## 2. Individualised Approaches & Social Approaches

### Recommendations

#### Recommendations for formal services;

- Health and Social Care professionals should consider care planning that follows a social model of support. Social prescribing should be practiced more widely in order to support people living with young onset dementia.
- More social peer groups or networks for people with young onset dementia and for families should be established to connect individuals experiencing similar situations.
- Dementia service providers should consider the establishment of a one-to-one peer support initiative.

#### Recommendations for community groups/organisations;

- People with young onset dementia should have access to supports and activities outside of mainstream dementia services. Community organisations should ensure they are inclusive and accessible to people with young onset dementia. Good channels of communication should be fostered between formal services and community organisations.
- A range of supports to promote wellbeing should be available, including arts, music, social outlets, and supports to optimise physical and mental health. Community groups should ensure their programs are widely publicised and include information on how supports can be accessed.

### Relevant Resources

- NICE Guidance on Person-centred care: [available here](#)
- Social prescribing guidance: [available here](#)
- Genio Person-Centered Care in the Community: [available here](#)
- ASI guidance on living with young onset dementia: [available here](#)
- Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways: [available here](#)
- SCIE – Living with young onset dementia: [available here](#)
- Engaging Dementia: [available here](#)

This list is not intended to be exhaustive\*

## Theme 3: Mapping and Signposting of Community Supports



People with young onset dementia often have specific and varied information needs. People with young onset dementia often experience many unique challenges relating to areas such as finances, legal matters, family support and support with the diagnosis.

Communication, clarity and consistency is vital for people with young onset dementia, and it is important to ensure that each person is allocated a nominated point of contact to provide support either at point of diagnosis or soon after diagnosis.

There are a wealth of innovative and invaluable community-based supports and initiatives available within our communities that might benefit a person with young onset dementia, and a key consideration is linking the person to these supports.

It is important that there is clarity in relation to relevant community-based supports and initiatives, and information on how these can be accessed. Community organisations can take steps to ensure they are accessible and contactable, for example, registering their organisation on national websites such as Understand Together.

### 3. Mapping and Signposting of Community Supports

#### Recommendations

##### Recommendations for formal services;

- All healthcare professionals working with people with young onset dementia need to be aware of the suite of relevant non-medical (and non-dementia) supports and services that are available in their location.
- Each person diagnosed with young onset dementia should be provided with a nominated point of contact in the community, to be established at point of diagnosis or as soon as possible thereafter.
- This point of contact should be knowledgeable of relevant community supports in that area.
- Online repository for community supports – Information resources on community-based supports should be compiled and circulated ideally by dementia service providers, preferably county by county.
- Social media to connect people / virtual social networks should be included in any mapping exercise to optimise accessibility for people with young onset dementia and families.
- Memory services, GPs, Health Centres etc. should familiarise themselves with key community-based supports in their area/country in order to signpost the person with young onset dementia, or be aware of how to access this information.

##### Recommendations for community groups/organisations;

- Local and national organisations who are dementia-inclusive or who wish to be inclusive of people with young onset dementia, should be identified and contact information included in an online repository for community supports.
- Community services (e.g., a library that is going to start holding a dementia evening) should contact local Dementia Advisors, the GP, The ASI and other dementia organisations to enlist on national dementia websites.

#### Relevant Resources

- Alzheimer Society of Ireland Dementia Advisor Service: [available here](#)
- Understand Together Service Finder: [available here](#)
- Dementia Advisors about/link to: [available here](#)
- Dementia Pathways for Health & Social Care Professionals: [available here](#)
- ASI Pathways to Care: [available here](#)
- Dementia Café Finder – Irish Dementia Café Network: [available here](#)
- Western Alzheimers: [available here](#)
- Dementia Services Information and Development Centre: [available here](#)
- Living Well with Dementia: [available here](#)
- Dementia Hub Ireland: [available here](#)
- ASI Service Finder: [available here](#)

This list is not intended to be exhaustive\*

## Theme 4: Making community supports more accessible for people with young onset dementia



There is a growing awareness of the important role that communities play in the lives of people with young onset dementia and their families. There are many ways in which we can improve our practices to become more accessible.

There are initiatives already underway in some communities, such as age friendly and dementia friendly initiatives, which could be further expanded to be inclusive of people with young onset dementia.

Community-based organisations should ensure they are accessible, and should consider ways to be inclusive of people with young onset dementia. Consideration should be given to ensure community-based activities are accessible and offered in a timely manner. Areas such as information design, inclusive messaging, transport and cost should be considered.

Community supports and resources should have access to support from dementia services and personnel, if required.

## 4. Making Community Supports more Accessible for People with Young Onset Dementia

### Recommendations

#### Recommendations for formal services;

- The organisations with a remit for policy and funding need to be cognisant of young onset dementia and the need to support people with young onset dementia, and their families.
- Primary Care Centres and Health Centres should work with dementia service providers to adopt timely signposting for people with young onset dementia.
- People with young onset dementia should be able to self-refer to attend certain community-based services and supports. This is particularly the case when people are waiting to receive a diagnosis or confirmation of diagnosis.
- There are key examples of community-based services which could be invaluable for people with young onset dementia, such as Citizens Information, Legal Aid Board, Money Advice and Budgeting Service, Workplace Relations Commission and similar. It is important that people with young onset dementia are signposted to these where necessary.
- Affordability is a key consideration – Health and Social Care providers should aim to signpost to supports that are affordable or cost neutral.
- Contact details of dementia service providers who are available to advise/assist on ways to become more inclusive for people with young onset dementia should be made available to community organisations (e.g., Training personnel, Learning & Development Officer).
- Community-based organisations/services who are developing supports or activities inclusive of people with young onset dementia should be provided with a nominated point of contact who can advise on issues relating specifically to young onset dementia (e.g., trained personnel)
- Flexible time provision should be considered to support people with young onset dementia, such as supports offered during evenings and weekends.

#### Recommendations for community groups/organisations;

- Advertising of community-based supports should be done through general media, including local radio and social media, to increase awareness of these supports for people with young onset dementia.
- In addition to in-person supports, information and communication technology should be utilised as an additional avenue to increase accessibility to supports in the community.
- Community supports must consider accessibility and transport and how people with young onset dementia will get to their services. For example, volunteer companions could assist with transport to and from supports or activities.
- To address stigma or reduced understanding in the community, people with young onset dementia should be offered visual indicators to alert staff that they might need extra time or assistance – e.g. 'Just A Minute' cards.
- Dedicated helplines should be made available to vulnerable customers within commonly used organisations, such as banks, credit unions and social welfare offices.

## Recommendations for community groups/organisations; *cont.*

- Information Design: Communities should consider the design of information to ensure its accessibility to people with young onset dementia. Examples include;
  - Provision of accessible information in written format that is available in the desired language of an individual.
  - Utilisation of neutral language.
  - Provision of dementia video resources to support community members without English literacy or where English is not a first language.
  - Use of clear, legible print and plain language in written communication. Information should avoid the use of jargon, and should include diagrams and images where useful.
  - Inclusivity and minority groups: providing documentation in different languages/preferred language of person with young onset dementia should be considered.
- Inclusive practices examples as reported by the literature and key stakeholders are as follows;
  - The nature, design and implementation of meaningful/effective community interventions are guided by people impacted by young onset dementia.
  - Use of virtually supported peer groups to support people with young onset dementia since numbers of people with young onset dementia can be low and there may not be a high number of people within certain locations/geographically challenged/isolated.
  - Within public spaces, regular quiet times offered, such as an hour in the morning available once weekly, to provide a calm space.
  - Within clubs, groups and activities, a volunteer support person is available to assist the person with young onset dementia.

## Relevant Resources

- UK young onset dementia-specific care pathway: [available here](#)
- Information on legal and capacity issues: [available here](#)
- Decision Support Service: [available here](#)
- Community Welfare Services: [available here](#)
- Department of Social Protection: [available here](#)
- Free Legal Advice Centre: [www.flac.ie](http://www.flac.ie) or (1890)350250
- Supported employment for people with disabilities – EmployAbility Services: [available here](#)
- Workplace Relations Commission: [available here](#)
- Citizens Information: [available here](#)
- Intreo Centres and local social welfare offices: [available here](#)
- Sage Advocacy: [available here](#)
- Transport for Ireland Jam Cards: [available here](#)
- Designing for Dementia: [available here](#)
- DEEP Guides on accessibility: [available here](#)

This list is not intended to be exhaustive\*



## Examples of community resources and groups

### Dementia-specific supports

- Dementia Cafés
- Dementia Befrienders
- Memory Technology Resource Rooms
- Interagency Dementia Friendly Groups
- Singing Groups (part of dementia cafés)
- Walking Groups (part of dementia cafés)
- Cognitive Rehabilitation/Stimulation – Memory Wellness Courses, online Memory Rehab
- Advocacy, Research and Policy engagement groups
- Dementia Advisors
- Dementia-specific support groups

### Community supports

- Community Development Workers
- Family Resource Centers
- ExWell programs – various locations
- Libraries – Trained librarians, sensory corners
- Walking groups in collaboration with the National Parks and Wildlife Service
- Men’s Sheds
- Tidy Towns
- JAM cards
- Rural Farming Initiatives
- Activities within Museums
- Choral Music Festivals
- Azure Arts Program

## Examples of community resources and groups

### Relevant Resources

- Community Centres: [available here](#)
- Family Resource Centres: [available here](#)
- Family Carers Ireland: [available here](#)
- Young dementia network: support after diagnosis: [available here](#)
- Dementia Cafe Manual: [available here](#)
- Irish Dementia Working Group: [available here](#)
- Your Shed and Dementia: A Manual: [available here](#)
- Sporting Memories Handbook – ASI/Understand Together: [available here](#)
- Azure Program: [available here](#)
- Dementia Support Groups: [available here](#)
- National Gallery of Ireland – dementia-inclusive activities: [available here](#)
- Community Walking Groups: [available here](#)
- Dementia Carers Campaign Network: [available here](#)

This list is not intended to be exhaustive\*







## THE ALZHEIMER SOCIETY *of* IRELAND

The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.



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