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Young onset and rarer forms of dementia

Collated national resources

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# Introduction

Dementia United, working with a range of partners, stakeholders and lived experience members, have collated information from a range of external organisations for people affected by dementia in Greater Manchester, including people living with dementia, carers, and practitioners.

The content below includes resources about young onset and rarer forms of dementia.

Please note that as the information collated is from external organisations **Dementia United is not responsible for these resources. This is not an exhaustive list of resources, it is intended to support you finding some key links and resources, where you would then be able to find out more information.**

Our intention is to review the resources and update this document twice a year. This review will be taken forward by the ‘young onset and rarer forms of dementia project group’, co-chaired by Dementia United and Jacqui Cannon, Lewy Body Society.

# National resources

## Young onset dementia

* There is a whole section on the Dementia UK website dedicated to young onset dementia which contains information about symptoms, getting a diagnosis and how to live with the condition as well as a unique database of age-appropriate support across the UK. [www.dementiauk.org/young-onset-dementia/](http://www.dementiauk.org/young-onset-dementia/)
* Young Dementia Network provides resources for people affected by young onset dementia, professionals, service providers, commissioners, and service developers. [www.youngdementianetwork.org/resources/](http://www.youngdementianetwork.org/resources/)
* [Establishing and sustaining high-quality services for people with young onset dementia: the perspective of senior service providers and commissioners](https://www.cambridge.org/core/journals/international-psychogeriatrics/article/establishing-and-sustaining-highquality-services-for-people-with-young-onset-dementia-the-perspective-of-senior-service-providers-and-commissioners/34DE3E858D64BB7D5E8BCF8E9B7E3A69?utm_campaign=shareaholic&utm_medium=twitter&utm_source=socialnetwork) [www.doi.org/10.1017/S1041610223000443](http://www.doi.org/10.1017/S1041610223000443)
* Decision making guide for doctors when considering referral pathways for diagnosing a younger person with dementia
* [www.youngdementianetwork.org/resources/guide-gps/](http://www.youngdementianetwork.org/resources/guide-gps/)
* Diagnosing dementia in younger people A decision-making guide for GPs [www.youngdementianetwork.org/wp-content/uploads/2023/01/V1\_YDN\_GP\_Guide\_Leaflet\_DL\_2022\_Web.pdf](http://www.youngdementianetwork.org/wp-content/uploads/2023/01/V1_YDN_GP_Guide_Leaflet_DL_2022_Web.pdf)
* A diagnosis of young onset dementia. The links below are to websites with information and support:
* [www.raredementiasupport.org/what-is-rare-dementia/](http://www.raredementiasupport.org/what-is-rare-dementia/)
* Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)
* [www.raredementiasupport.org/young-onset-alzheimers-disease](http://www.raredementiasupport.org/young-onset-alzheimers-disease)
* [www.alzheimers.org.uk/about-dementia/types-dementia/what-causes-young-onset-dementia](http://www.alzheimers.org.uk/about-dementia/types-dementia/what-causes-young-onset-dementia)

## Alcohol-related brain impairment

Alcohol-related brain damage (ARBD) is an umbrella term used to describe the damage that can happen to the brain as a result of long-term heavy drinking. We have provided information on **alcohol-related brain impairment (ARBD) under the young onset dementia resources**, as most people with ARBD are in their 50s and 60s, but more and more people in their 30s and 40s are being seen with symptoms. Typically, women develop ARBD at a younger age than men.

We have provided links below, to resources that you may find useful.

* [www.alcoholchange.org.uk/alcohol-facts/fact-sheets/alcohol-related-brain-damage-what-is-it](http://www.alcoholchange.org.uk/alcohol-facts/fact-sheets/alcohol-related-brain-damage-what-is-it)
* [www.alzheimers.org.uk/about-dementia/types-dementia/alcohol-related-dementia#content-start](http://www.alzheimers.org.uk/about-dementia/types-dementia/alcohol-related-dementia#content-start)

## Rarer forms of dementia

There are many other diseases and conditions that can lead to dementia. These conditions are rarer, can occur at a younger age, and can cause symptoms that are not only memory-related.

* Website with information and support about rarer forms of dementia [www.raredementiasupport.org/what-is-rare-dementia/](http://www.raredementiasupport.org/what-is-rare-dementia/)
* Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)

We have provided further links to information and resources, from external organisations, on some of the rarer forms of dementia in a little more detail below.

### Lewy body dementia

* Signs and symptoms of Lewy body dementia can be hard to detect, often leading to missed or misdiagnosis. The DIAMOND Lewy toolkit is intended to support assessment for early detection and diagnosis of Lewy body dementia <https://research.ncl.ac.uk/diamondlewy/>
* This management guideline provides evidence based practical advice on the assessment, treatment pathway and management along with the one page symptom summary sheets  [https://research.ncl.ac.uk/media/sites/researchwebsites/diamond-lewy/Management%20Guideline%20for%20LBD.pdf](%20https://research.ncl.ac.uk/media/sites/researchwebsites/diamond-lewy/Management%20Guideline%20for%20LBD.pdf)
* The Lewy Body Society resources raise awareness and link to information <https://research.ncl.ac.uk/media/sites/researchwebsites/diamond-lewy/Management%20Guideline%20for%20LBD.pdf>
* The Lewy Body Society resources raise awareness and link to information and support [www.lewybody.org/ information-and-support](http://www.lewybody.org/%20information-and-support)
* Admiral Nurse for Lewy body dementia [www.lewybody.org/admiral-nurse-dementia-helpline-here-to-help/](http://www.lewybody.org/admiral-nurse-dementia-helpline-here-to-help/) You can contact the helpline on **0800 888 6678**and it is available Monday to Friday 9am-9pm and Saturday and Sunday 9am-5pm.
* The Lewy body Community of Practice [www.lewybody.org/professional-resources/community-of-practice/](http://www.lewybody.org/professional-resources/community-of-practice/)
* A website with information and support about rarer forms of dementia [www.raredementiasupport.org/what-is-rare-dementia/](http://www.raredementiasupport.org/what-is-rare-dementia/)
* Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)

### Frontotemporal dementia (FTD)

* The association of FTD website provide information and sources of support [www.theaftd.org/what-is-ftd/disease-overview/](http://www.theaftd.org/what-is-ftd/disease-overview/)
* Dementia UK provide information on FTD [www.dementiauk.org/information-and-support/types-of-dementia/frontotemporal-dementia/](http://www.dementiauk.org/information-and-support/types-of-dementia/frontotemporal-dementia/)
* A website with information and support about rarer forms of dementia. [www.raredementiasupport.org/what-is-rare-dementia/](http://www.raredementiasupport.org/what-is-rare-dementia/)
* Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)

### Primary progressive aphasia

Primary progressive aphasia (PPA) is a term that refers to a group of dementias that affect a person’s speech and language.

* + - Alzheimer’s Research UK information leaflet on PPA [www.alzheimersresearchuk.org/wp-content/uploads/2023/10/PPA\_0423\_0425\_WEB.pdf](http://www.alzheimersresearchuk.org/wp-content/uploads/2023/10/PPA_0423_0425_WEB.pdf)
    - Rare dementia support have information and support with a focus on progressive nonfluent aphasia (PNFA), semantic dementia (SD) and logopenic aphasia (LPA) [www.raredementiasupport.org/primary-progressive-aphasia/](http://www.raredementiasupport.org/primary-progressive-aphasia/)
    - Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)

Speakeasy provide support, raise awareness about aphasia [www.speakeasy-aphasia.org.uk/aphasia/how-can-we-help](http://www.speakeasy-aphasia.org.uk/aphasia/how-can-we-help). They accept referrals from across all of Greater Manchester. The person themselves, a family member or health and care professional can make a direct referral: [www.speakeasy-aphasia.org.uk/referrals/](http://www.speakeasy-aphasia.org.uk/referrals/) and [www.speakeasy-aphasia.org.uk/about/regular-activities/](http://www.speakeasy-aphasia.org.uk/about/regular-activities/)

### Posterior cortical atrophy

Posterior cortical atrophy (PCA) is a rare form of dementia which can initially cause difficulties with seeing what and where things are, for example, when you’re driving or reading.

* Information and support from the rare dementia support website. [www.raredementiasupport.org/posterior-cortical-atrophy/](http://www.raredementiasupport.org/posterior-cortical-atrophy/)
* Lived experience stories [www.raredementiasupport.org/stories/](http://www.raredementiasupport.org/stories/)

# Links to other useful resources

**Admiral nurses** provide support to family carers and people living with dementia throughout the trajectory of dementia, particularly during complex periods of transition.They also provide education, leadership, development and support to other colleagues and service providers.

**National Admiral Nurse Helpline, Dementia UK**

Call 0800 888 6678

Email [helpline@dementiauk.org](mailto:helpline@dementiauk.org) for advice and support and to access the following national Consultant Admiral Nurses (offering virtual appointments):

* LGBTQ+ Admiral Nurse
* Frailty Admiral Nurse
* Children and Young People Admiral Nurse
* Young Onset Dementia Admiral Nurse
* Lewy Body Admiral Nurse

**Collated national resources on Dementia United’s webpage**

The links below take you to Dementia United’s collated national resources focusing on quality and experience of diagnosis, dementia education and training and distressed behaviours projects that will also be of value:

* [www.dementia-united.org.uk/useful-national-resources-quality-of-diagnosis](http://www.dementia-united.org.uk/useful-national-resources-quality-of-diagnosis/)
* [www.dementia-united.org.uk/useful-national-resources-distressed-behaviours](http://www.dementia-united.org.uk/useful-national-resources-distressed-behaviours)

# Contact us

If you have any questions about the information or further resources you would wish us to consider for the page, please email Dementia United.

Email: [gmhscp.dementiaunited@nhs.net](mailto:gmhscp.dementiaunited@nhs.net)