Support for people with young onset dementia and their families to help manage the financial impact of living with the condition

This resource was produced from **the DYNAMIC research project** which looked at social care planning and provision for people with young onset dementia and their families. One of the key priority areas of the project was to improve strategies to help manage the financial impact of living with young onset dementia. Researchers completed a review of leaflets and literature on this topic which informs this information sheet.

All included sources of information, help and advice relate to key financial issues associated with living with young onset dementia. It covers benefits and entitlements, managing the costs of care, managing your money, employment, early retirement and pensions and legal considerations.

It may be useful to people with young onset dementia, their families and social care professionals, in their role of supporting people with young onset dementia and their families.

Benefits and entitlements

Alzheimer's Society

Provides information about **personal budgets** including how to get an assessment and the process involved. It also give advice on **managing a personal budget** including Individual Service Funds and Direct Payments. Its booklet **Understanding young onset dementia** has a section on financial support and benefits.

The charity also provide information on **carers assessments** and the criteria that a carer must meet for the local authority to consider funding their care and support.

Dementia UK

Provide a leaflet on **finance and young onset dementia** which has advice on benefits and grants as well as a list of other benefit-related resources to follow up on. Its webpages have relevant **information** too.

Carers UK

Provide information about what you could be entitled to, including: **Carer's Allowance**, **Pension Credit**, **Support for those who are disabled, ill or injured**, **Support for carers who are working age**. It also has a **Benefits calculator** and give support for **form filling** including this short **video**.

Job Centre Plus
A government-funded employment agency and social security office that can be found in most cities. It provides employment services and administers benefits claims. Disability Employment Advisors, based in Job Centre Plus, can give advice on universal credit application and entitlements (but do not support PIP claims).

Younger people with dementia: living well with your diagnosis
This booklet produced by Alzheimer Scotland – Action on Dementia has information on claiming benefits. (NB advice may vary depending on where you live in the UK).

Managing the costs of care

Alzheimer's Society

The booklet **Understanding young onset dementia** has a section on paying for social care and support.

Care confidence
This tool is designed to help you feel better prepared to make decisions about paying for social care. Using Care confidence may help with the following:

- making life easier at home
- moving to a different home or to a care home
- thinking about money and managing money whilst paying care home fees

Carers UK
Provide information about getting **help with health and care costs** including a **Guide to saving on health and care costs**, **NHS Continuing Healthcare**, **Direct Payments** , **Personal budgets** and **Disability benefits**. There is also information about getting extra financial advice through **Grants and schemes**.

Dementia UK
Provide a **Guide to continuing healthcare (CHC) funding**. CHC applies to England and Wales only; a different system applies in Scotland called **Hospital Based Complex Clinical Care**, but this only covers care in hospital settings.

Managing your money

Alzheimer's Society

The booklet on **Understanding young onset dementia** has a section on managing your money. The charity also produce a broader booklet about **managing your money** when you have dementia. This includes information and advice about using and managing money now and in the future, getting more support and keeping your money safe.

Dementia UK
Its leaflet on **finance and young onset dementia** has advice on day to day financial management. Its webpages have relevant **information** too.

Carers UK
Provide advice for managing money such as **help with bills and household costs**, **dealing with debt** and **keeping safe from scams**.

MoneyHelper
Provides free impartial money guidance for people in the UK, backed by the government. It offers guidance on benefits, family and care, savings, homes, pensions and retirement. You can phone MoneyHelper for money guidance on 0800 1387777 from Monday to Friday or make contact **online**.

If you are worried about debt you can **contact** MoneyHelper for free confidential advice and read **information on dealing with debt** online. There are also guides for managing **the cost of living**. Using its **budget planner** can help you to get control of your household spending. There is also **guidance of what to do** if you think you have been scammed.

Society of Later Life Advisors (SOLLA)
SOLLA provides accessible regulated financial advice for people where decisions associated with later life come early, such as in young onset dementia. All financial advisers listed on the website directory have been assessed and are accredited in their role. Use the **find an advisor tool** to locate a local Later Life accredited advisor. Accredited advisers can advise on retirement planning including pensions and annuities, funding care, equity release and other property options, savings and investment planning, tax matters and estate and wealth planning.

The Financial Ombudsman Service
A free and easy to access service if you have a complaint or need help to resolve financial issues. **How to complain**.

Younger people with dementia: living well with your diagnosis
This Alzheimer Scotland – Action on Dementia booklet has information on managing your money. (NB advice may vary depending on where you live in the UK).

Dementia-friendly finance and insurance guide: a practical guide for financial services and insurance providers to support people affected by dementia
Published by Alzheimer's Society in 2018 this guide was developed for the financial services and insurance sector (banks, building societies, insurance companies and asset management companies).

Employment, pensions and early retirement

Dementia UK

Its leaflet on **finance and young onset dementia** has advice on employment, pensions and retirement. Its webpages have relevant **information** too.

Younger people with dementia: living well with your diagnosis

This Alzheimer Scotland – Action on Dementia booklet has information on work and employment. (NB advice may vary depending on where you live in the UK).

Supporting social care practice for people with young onset dementia and their families

This resource, developed in connection with the DYNAMIC project, has relevant sections on employment and meaningful occupation including links to advice and information.

Government advice on early retirement, pensions and benefits

This link will take you to the gov.uk website where official advice is provided about early retirement, pensions and benefits.

Legal considerations

Alzheimer's Society

The booklet, **Understanding young onset dementia**, has a section on Power of Attorney.

Dementia UK

The leaflet **finance and young onset dementia** has advice on legal matters with links to relevant organisations in the 'other resources' section at the end. Its webpages have relevant **information** too including a downloadable **Lasting Power of Attorney leaflet**.

Legal and financial issues: support for family carers providing personal care for people living with dementia

This booklet, published in 2024 by the University of Worcester, covers topics such as mental capacity to make decisions and choices, Lasting Powers of Attorney, Advanced Care Planning and Advance Decisions, Advance Directives and Attendance Allowance.

Financial Securi-tea, Young Dementia Network webinar

This **webinar** given in 2021 covered financial issues affecting people with young onset dementia and their families including planning, problem solving and protecting yourself from scams.

My Choice

This 2024 booklet gives people with dementia and their carers evidence-based information on living well with dementia, including on planning for the future and financial support. It was developed by the Applied Research Collaboration and

Health Innovation Kent Surrey Sussex and co-designed with people with lived experience of dementia.

Younger people with dementia: living well with your diagnosis
This Alzheimer Scotland – Action on Dementia booklet has information on legal considerations and planning for the future. (NB advice may vary depending on where you live in the UK).

Research papers and surveys

Family members' experiences of young-onset dementia: becoming responsible yet feeling powerless

Family carers' narratives of the financial consequences of young onset dementia

Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: Results of an online survey

Clinical nurse specialist's role in young-onset dementia care [NB not open access]

Services for people with young onset dementia: The 'Angela' Project national UK survey of service use and satisfaction

Tide: carers of people living with young onset dementia **survey findings**.

A specialist welfare advice and advocacy service for people with early onset dementia [NB not open access]

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For more information about the DYNAMIC resource project visit:
youngdementianetwork.org/DYNAMIC

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The **Young Dementia Network** is an online membership community for everyone living with, working with or interested young onset dementia. Join for free **here**.

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