



# **Carer's Handbook**

## **For those caring for people living with dementia in Northern Ireland**



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## Introduction

‘There are too many hoops, places to look, people to speak to and different services to know about. My mind is crowded with the phone calls, the appointments, the chasing and remembering.’

This handbook is for anyone caring for someone with dementia. The idea came from carers who were exhausted having to search for the information they needed, particularly when they didn’t have the time or energy for it. We understand that the dementia journey for a carer is an unpredictable and, at times, all consuming role that you may not have asked for.

We aim to give you information that will be useful in your journey as carers for someone with dementia. There is information about carer and dementia organisations and about the different services provided by them and by the government. There is also information about benefits, financial and legal matters and the advice and advocacy organisations that can help. Information on your human rights as a carer and the organisations who help to protect these rights, is also included.

We have tried to write in a way that’s understandable and useable. There is an explanation for all the terms. Carers have been involved in writing parts of this handbook and in editing it all.

**We are tide:** a network of present and former carers of people with dementia. In Northern Ireland we work to connect carers with each other; provide opportunities for creative ways to express how it is to be a carer, to provide information and skills and work towards influencing for change. Any present or former carer of someone with dementia can join, for free and participate in whatever way suits them. If you are interested in finding out more, or perhaps becoming a part of our collective voice, please contact us:

✉ [Fiona@tide.uk.net](mailto:Fiona@tide.uk.net) or [Beverley@tide.uk.net](mailto:Beverley@tide.uk.net) or [carers@tide.uk.net](mailto:carers@tide.uk.net) (UK)

🌐 [www.tide.uk.net](http://www.tide.uk.net)

📞 07841 457596 / 07841421158 / 0151 2372669 (UK)

✉ c/o Age NI, 3 Lower Crescent, Belfast

📘 @tidecarers

🐦 #tide\_carers

# 1 Useful community and voluntary sector organisations

## 1.1 Carers Support

### Age NI

Age NI is a regional organisation which provides information and support for older people (60+) and their carers. Age NI offers independent and confidential advice, information and support to older people, their families and carers on a range of issues in later life including money, care, housing and health.

 [info@ageni.org](mailto:info@ageni.org)

 <https://www.ageuk.org.uk/northern-ireland/#>

 028 9024 5729

 3 Lower Crescent, Belfast BT2 7NR

 @Age\_NI

 @agenicharity

### Age Concern Causeway

Age Concern Causeway provides a range of social and support services for older people in the Causeway Coast & Glens area. Services include Active Age social activities, Advocacy & Information, Befriending and Dementia Support.

 [info@accauseway.org](mailto:info@accauseway.org)

 [www.accauseway.org](http://www.accauseway.org)

 028 7035 7966

 3 Brook Street, Coleraine BT52 1PW

 @AgeConcernCauseway

 @AgeConcernCW

### Action for Children

Their support helps young adult carers come to terms with their parent's or other family member's illness or condition. They work with young adult carers on how to cope and guide them to build positive relationships outside the family. Action for Children work across all five Health & Social Care Trust areas.

 [youngadultcarers@actionforchildren.org.uk](mailto:youngadultcarers@actionforchildren.org.uk)

 [www.actionforchildren.org.uk/our-work-and-impact/children-and-families/young-carers/](http://www.actionforchildren.org.uk/our-work-and-impact/children-and-families/young-carers/)

 02890460500

✉ Young Adult Carers Support Service, Loughshore House, 10 Heron Raod, Belfast BT3 9LE

f @actionforchildren

t @actnforchildren

### **Barnardos**

Barnardos helps young carers look after their loved ones and give them time to enjoy their childhoods. They operate in the Western and Northern Trust areas

@ ReceptionNI@barnardos.org.uk

globe [www.barnardos.org.uk/what-we-do/helping-families/young-carers](http://www.barnardos.org.uk/what-we-do/helping-families/young-carers)

whatsapp 028 9067 2366

✉ 542 - 544 Upper Newtownards Road, Belfast, BT4 3HE

f @BarnardosNI

t @BarnardosNI

### **Care Home Advise and Support Northern Ireland (CHASNI)**

**Supporting residents and families with all things care home related**

t @JulieannNally

### **Carers NI**

Carers NI is a carer-led membership charity providing an enquiry service for carers and professionals in addition to support for carers through groups and branches and campaigns to improve carers rights. It supports carers across Northern Ireland.

@ [info@carersni.org](mailto:info@carersni.org)

globe [www.carersni.org](http://www.carersni.org)

whatsapp 0808 808 7777 (Helpline) 028 9043 9843 (Office)

✉ 58 Howard Street, Belfast, BT1 6PJ

f @CarersNI

t @CarersNI

### **Carers Trust Northern Ireland (Southern Trust only)**

Carers Trust Northern Ireland works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Carers Trust is only operational in the Southern Trust area. They provide a helpline and information service, events and activities. An outreach and information support service is also available. There is also a regular newsletter which you can sign up to.

@ [price@carers.org](mailto:price@carers.org)

 <https://carers.org/our-work-in-northern-ireland/our-work-in-northern-ireland>

 07826 930508

 @carerstrust

 @CarersTrustNI

### **Crossroads Caring for Carers NI**

Crossroads promotes, offers, supports and delivers services for carers and the people they care for across Northern Ireland.

 [info@crossroadscare.co.uk](mailto:info@crossroadscare.co.uk)

 [www.crossroadscare.co.uk](http://www.crossroadscare.co.uk)

 028 9181 4455

 432 Upper Newtownards Road, Belfast, BT4 3GY

 @crossroadsni

 @crossroadsni

And of course – tide (our details are in the introduction and on the back of this handbook.)

## 1.2 Dementia support

### Alzheimer's Society NI

The Alzheimer's Society provides information, advice and support groups for people with all forms of dementia and their carers across Northern Ireland. There are carer support groups running in some areas in addition to an online forum for carers, called Talking Point plus a wide range of very helpful factsheets available on their website, for example: Factsheet 'Carers - looking after yourself': <https://www.alzheimers.org.uk/get-support/help-dementia-care/looking-after-yourself>

✉ [nir@alzheimers.org.uk](mailto:nir@alzheimers.org.uk)

🌐 [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

☎ 028 9066 4100 (Office) 0300 222 11 22 (UK Dementia Connect Helpline)

✉ Unit 4, Balmoral Business Park, Boucher Crescent, Belfast, BT12 6HU

f @AlzheimersSocietyNorthernIreland

🐦 @AlzSocNI

### Dementia Friendly Communities

Dementia Friendly is an initiative which aims to make Belfast a friendlier place for people living with dementia and make daily living and activities easier and more accessible. It also aims to support families, carers, friends of people with dementia and older people generally. The campaign is supported by Belfast Health and Social Care Trust and the Public Health Agency.

### Dementia Friendly East Belfast

✉ [dementiafriendlyeastbelfast@gmail.com](mailto:dementiafriendlyeastbelfast@gmail.com)

🌐 <https://www.dementiafriendlyeastbelfast.com>

f <https://www.facebook.com/DementiaFriendlyEastBelfast>

🐦 @DementiaEastBel

### Dementia Friendly North Belfast

✉ [dementiafriendlynorthbelfast@gmail.com](mailto:dementiafriendlynorthbelfast@gmail.com)

f <https://www.facebook.com/DementiaFriendlyNorthBelfast>

### Dementia Friendly South Belfast

✉ [dementiafriendlysouthbelfast@gmail.com](mailto:dementiafriendlysouthbelfast@gmail.com)

f <https://www.facebook.com/dfsouthbelfast>

### Dementia Friendly West Belfast

✉ [dementiafriendlywestbelfast@gmail.com](mailto:dementiafriendlywestbelfast@gmail.com)

## **Dementia NI**

Dementia NI is a NI charity set up by people living with dementia to enable them to have their voices heard and improve services for themselves and others. There are Dementia Empower and Support Groups across Northern Ireland in each of the health trust areas. Dementia NI also provide the Just A Minute [JAM] Card, which states: "Please be patient. I have dementia/memory problems and may need assistance."

@ [info@dementiani.org](mailto:info@dementiani.org)

🌐 [www.dementiani.org](http://www.dementiani.org)

📞 028 9693 1555

✉️ North City Business Centre, 2 Duncairn Gardens, Belfast, BT15 2GG

f @DementiaNI

🐦 @Dementia\_NI

## **Huntington's Disease Association Northern Ireland (HDANI)**

HDANI works throughout Northern Ireland providing support, information, advice and social connections to those living with the impact of Huntington's Disease. Huntington's Disease can develop into a type of dementia. They run regional support groups, provide telephone and face to face advice and support as well opportunities for families to connect.

@ [zelie@hdani.org.uk](mailto:zelie@hdani.org.uk) / [sorcha@hdani.org.uk](mailto:sorcha@hdani.org.uk)

🌐 <http://www.hdani.org.uk>

📞 079 8284 3907

✉️ 53 Andersonstown Road, Belfast, BT11 9AG

f [@HDANorthernIreland](https://www.facebook.com/HDANorthernIreland)

## **Marie Curie**

Marie Curie is the end of life charity, which provides frontline nursing and hospice care, a free support line and information and support on all aspects of dying, death and bereavement. They work across Northern Ireland.

🌐 [www.mariecurie.org.uk/help/support/benefits-entitlements](http://www.mariecurie.org.uk/help/support/benefits-entitlements)

📞 028 9433 1868 (NI switchboard) / 0800 090 2309 (helpline)

✉️ 1A Kensington Road, Belfast, BT5 6NF

f @MarieCurieNI

🐦 @MarieCurieNorthernIreland

## **National Activities Providers Association (NAPA)**

NAPA supports care teams in helping make older people's lives easier, to enable them to live their lives with meaning and purpose. Their values are based on the uniqueness of the person and person-centred meaningful engagement over which the person has choice and control.

 [info@napa-activities.co.uk](mailto:info@napa-activities.co.uk)  
[helpline@napa-activities.co.uk](mailto:helpline@napa-activities.co.uk)

 <http://napa-activities.co.uk/>

 0207 078 9375 / 0800 1585503

### **Northern Ireland Hospice**

Northern Ireland Hospice provides specialist palliative care to adults and children with life threatening and life limiting disease. It also offers a service for adult carers and bereavement support.

 [info@nihospice.org](mailto:info@nihospice.org)

 [www.nihospice.org](http://www.nihospice.org)

 028 9078 1836

 Adults Hospice, 74 Somerton Road, Belfast, BT15 3LH

 @NIHospice

 @NIHospice

### **Praxis Care**

Praxis Care supports vulnerable children and adults with a range of complex needs due to learning disabilities, mental ill health, acquired brain injury or dementia through the provision of care and accommodation.

 [info@praxiscare.org.uk](mailto:info@praxiscare.org.uk)

 [www.praxiscare.org.uk](http://www.praxiscare.org.uk)

 028 9023 4555

 25-31 Lisburn Road, Belfast, BT9 7AA

 @praxiscare

 @praxiscare

## Radius Housing

Help with modernising and adapting your home. Staying Put Solutions can assist you by managing a range of minor adaptations and improvements to your home such as personal alarms.

✉ [stayingput@radiushousing.org](mailto:stayingput@radiushousing.org)

🌐 [www.radiushousing.org/care-and-support/support/home-adaptations/need-help-to-modernise-or-adapt-your-home](http://www.radiushousing.org/care-and-support/support/home-adaptations/need-help-to-modernise-or-adapt-your-home)

[www.radiushousing.org/assets/documents/staying-put-service-and-nihe-grant-scheme.pdf](http://www.radiushousing.org/assets/documents/staying-put-service-and-nihe-grant-scheme.pdf)

📞 02890 397173

## Three Nations Dementia Working Group (3NDWG)

The 3NDWG is a group of people living with dementia across England, Northern Ireland and Wales. Members are based in all three nations, creating a network of voices on dementia who lead on regional projects.

✉ [3NDWG@alzheimers.org.uk](mailto:3NDWG@alzheimers.org.uk)

🌐 <https://www.3ndementiawg.org/>

📘 @3NDWG

🐦 @3NDWG

And of course – tide (our details are in the introduction and on the back of this handbook).

## 2 Carer services led by Health and Social Care Trusts

### 2.1 Primary Care Services - your GP practice

Primary Care - that is all the services provided by your GP practice - can act as your first point of contact and as a 'gateway' to a wide variety of services, both within the primary care system itself and to other parts of the wider health and social care system.

Make an appointment at your local GP surgery to discuss your health or social care needs with the Practice Nurse or your GP, who will provide any information that you require and can refer you to the appropriate care professionals where necessary.

Among other things, your GP makes referrals to a different health and social teams, memory clinic or assessment centre, occupational therapist for example, if housing needs adaptations. Your GP may be able to refer you for support e.g. counselling, befriending, local groups. They can also refer you for a carers assessment and respite care (or short break). If the person you are caring for does not have a diagnosis of dementia, and you or they are concerned that they have been more forgetful or confused or behaving 'out of character' - your GP is your first port of call.

### 2.2 Health and Social Care Trusts : Carer Coordinators

Each health trust area has a Carer Coordinator who is a point of contact for family carers. They can tell you about:

- Local support
- Carer's assessments
- Breaks from caring and respite care
- Activities and training opportunities
- Other health trust services and other support organisations

They can also inform you of events and carer support groups in your area, benefits advice, potential grants and much more to help you maintain your health and wellbeing in your caring role.

Carers can register on the Health and Social Care Trust's Carer's List, which is sometimes called a Register. If you choose to join this list, you can also keep up-to-date with information, services and initiatives that may support you in your caring role; ensure that you are aware of your rights and entitlements as a carer; find out about any proposed changes to services that may affect you or the person you care for and have opportunities to have your voice heard. To register, contact the Carer Service in your Health Trust area.

If you are an unpaid carer for a person who is known to the health or social services, you may be entitled to a Carer ID card. Contact the Carer Service in your health trust area.

<https://www.health-ni.gov.uk/news/new-id-card-carers-launched>

## **Belfast Health and Social Care Trust**

**Carer Co-ordinator** Margaret McDonald

 [CarerSuppSvcs@belfasttrust.hscni.net](mailto:CarerSuppSvcs@belfasttrust.hscni.net)

 <https://belfasttrust.hscni.net/service/carers-services/>

 028 9504 2126

 3rd Floor, Arches Health and Wellbeing Centre, 1 Westminster Avenue North,  
Belfast, Co Antrim, BT4 1NS

 @BelfastTrust

 @BelfastTrust

## **Northern Health and Social Care Trust**

**Carer Co-ordinator** Claire Campbell

**Carer Support** Gillian Bradley

 [carers.coordinator@northerntrust.hscni.net](mailto:carers.coordinator@northerntrust.hscni.net)

 <https://www.northerntrust.hscni.net/services/carers-service/>

 028 2766 1210

 Route Complex, 8E Coleraine Road, Ballymoney, BT53 6BP

 @NHSCTrust

 @NHSCTrust

## **South Eastern Health and Social Care Trust**

**Carers Co-ordinator** Pamela Smith

**Carers Support** Sharon Graham

 [carer.support@setrust.hscni.net](mailto:carer.support@setrust.hscni.net)

 <https://setrust.hscni.net/wp-content/uploads/2019/09/Carer-Info-Booklet-2020-Sept-2020.pdf>

 028 4372 1807

 Ballynahinch Community Services, 45 - 47 Main Street, Ballynahinch, BT24 8DN

 @SouthEasternHealthSocialCareTrust

## Southern Health and Social Care Trust

**Carers Co-ordinator** Clare Forsythe

 [carers.coordinator@southerntrust.hscni.net](mailto:carers.coordinator@southerntrust.hscni.net)

 <https://southerntrust.hscni.net/health-wellbeing/community-development-and-user-involvement/carers-information/>

<https://carers.org/downloads/general-pdfs/carersupportservicenorthernireland.pdf>

 028 3756 6284

 Promoting Wellbeing Team, John Mitchel Place, Newry, Co Down, BT34 2BU

 @SouthernHSCT

 @SouthernHSCT

## Western Health and Social Care Trust

**Carer Co-ordinator** Cathy Magowan

 [carers.Support1@westerntrust.hscni.net](mailto:carers.Support1@westerntrust.hscni.net)

 [carers.Support1@westerntrust.hscni.net](https://westerntrust.hscni.net/service/carers-support-service/)

 028 6634 4163

 2 Coleshill Road, Enniskillen, Co. Fermanagh, BT74 7HG

 @WesternHSCTrust

 @WesternHSCTrust

**Carers Development** Geraldine McLaughlin

 [carers.Support1@westerntrust.hscni.net](mailto:carers.Support1@westerntrust.hscni.net)

 <https://westerntrust.hscni.net/service/carers-support-service/>

 028 7135 5023

 Rossabbey Office, Abbey Street, Derry/Londonderry, BT48 9DN

 @WesternHSCTrust

 @WesternHSCTrust

## 3 Dementia services led by Health and Social Care Trusts

### 3.1 Accessing services

If you are concerned that the person you are caring for has become more forgetful, or has been feeling confused, anxious or behaving out of character, you may like to suggest that they speak to their GP and you accompany them for the appointment. The GP can advise on diagnosis and what services are available and how to be referred for services such as the Memory Clinic or assessment centre.

 <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/diagnosis>

<https://www.nidirect.gov.uk/articles/getting-diagnosed-dementia>

<https://www.nidirect.gov.uk/articles/gp-out-hours-service>

#### **Dementia Navigators**

Once a person has received a diagnosis of dementia, they can be referred to a Dementia Navigator. A Dementia Navigator will support any person who has received a new diagnosis of Dementia; someone with an existing diagnosis who may require additional support; and family and carers. The person has to give their consent to be referred to the Dementia Navigator.

#### **Mental Health / Older People's Teams**

Provides specialist community based mental health support for people who are over the age of 65 and experiencing a mental illness and people of all ages living with dementia and their carers. This team mostly focuses on supporting people who are displaying challenging behaviours and support them and their carers in finding strategies to deal with these.

#### **Memory Clinic / Services**

For anyone aged 65 and over who has experienced memory problems for 6 months or more, where their GP has ruled out other causes. The Memory Clinic carries out assessment and diagnosis. Once the person has received a diagnosis of dementia, they can be referred to the Dementia Navigator. You are referred to the Memory Clinic by your GP, so if you or the person you are caring for is concerned, the first person to speak to is your GP.

#### **Sensory Support Service**

Sensory Support Service provide services for people with significant sight loss, who are Deaf, hard of hearing or who have both sight and hearing loss. They aim to reduce the impact sensory loss has on your daily life, focusing on individual needs. This is done through specialist assessment and care planning with the aim of limiting the impact that sensory impairment has on daily living.

#### **CLEAR Dementia Care© App**

Developed within the Northern Trust, the CLEAR Dementia Care App provides accessible information and support. The App includes a function to help record and chart behaviour. Search for 'clear dementia care' on the iOS app store or google play or on the Trust's website

 <http://www.northerntrust.hscni.net/services/dementia-services/clear/clear-dementia-care-app/> .

## Belfast Health and Social Care Trust

### Dementia Navigators

If you would like to refer to The Dementia Navigator Service, referrals are currently being made via:

📧 [SinglePointMHSOP@belfasttrust.hscni.net](mailto:SinglePointMHSOP@belfasttrust.hscni.net)

🌐 <https://belfasttrust.hscni.net/service/dementia-navigator/>

<https://belfasttrust.hscni.net/service/dementia-services/dementia-resources/>

📞 028 95042700

### Mental health and older people's services

Belfast Trust has the same single contact number/point for all outpatient referrals to the Belfast Psychiatry of Old Age (POA) and the Community Mental Health Team for Older People (CMHTOP), as well as the Dementia Navigators service.

📧 [SinglePointMHSOP@belfasttrust.hscni.net](mailto:SinglePointMHSOP@belfasttrust.hscni.net)

🌐 [Dementia Resources | Belfast Health & Social Care Trust \(hscni.net\)](https://belfasttrust.hscni.net/service/older-peoples-services/)

<https://belfasttrust.hscni.net/service/older-peoples-services/>

📞 028 9504 2700

### Psychiatry of Old Age

Consultant led medical team which includes the Memory Clinic, which among other things, conducts memory assessments and diagnosis. Referrals are made through GP.

### Community Mental Health Team for Older People

This team provides specialist community based mental health support for people across the Belfast Trust area who are over the age of 65 and experiencing a mental illness and people of all ages living with dementia and their carers. This team mostly focuses on supporting people who are displaying challenging behaviours and support them and their carers in finding strategies to deal with these.

### Community Social Work Team

The Community Social Work Team work to support you or the person with dementia that you are caring for, to get the support you need. You can be referred by your GP or other health professional; and you can also refer yourself/person you are caring for, by contacting:

📞 North and West Belfast Call Management Centre: 028 9615 8100

South and East Belfast Call Management Centre: 028 9615 8200

### Sensory Support Service

One of the most used services we refer to is the Hearing Aid Volunteer Service from RNID, contact on 07918112290. This is a highly recommended service for people who need help with hearing aid maintenance and advice.

📧 [sensorysupport@belfasttrust.hscni.net](mailto:sensorysupport@belfasttrust.hscni.net)

 <https://belfasttrust.hscni.net/service/sensory-support/> (video)

 02895 040200 / SMS 07738883116 / Mob 07738883116

 Bradbury Centre, 1-17 Lisburn Rd, Belfast, BT9 7AA

## **Northern Health and Social Care Trust**

### **Dementia Navigators**

Dementia navigators are social workers, and work alongside the 'Memory Link Worker' in their areas. (For those with no named worker who receive a new dementia diagnosis the Dementia Navigator will offer a post diagnostic assessment.) A person-centered support plan will be developed and the person with dementia and their carer and family members will be signposted to appropriate services.

 <http://www.northerntrust.hscni.net/services/dementia-services/dementia-navigator/>

 028 9441 5767

### **Mental health and older people's services**

There are seven Community Mental Health Teams for Older People (CMHTOP) based in four Northern Trust geographical localities. Staffing within CMHTOP includes medical, nursing, social work, occupational therapy, support staff and administrative staff. The multidisciplinary teams provide a range of services to individuals with mental health needs to include, individuals living with a dementia irrespective of age, and individuals with a mental illness aged over 65. In addition the teams provide a range of services and supports for carers of individuals known to CMHTOP. The aim of each CMHTOP is to enable each service user and their carer to be supported to lead as independent a life as possible.

 <http://www.northerntrust.hscni.net/services/community-mental-health-teams-older-people/>

 028 9441 3650 - Antrim/Ballymena

028 7936 5091 - Cookstown / Magherafelt

028 9442 4322 - Larne / Carrickfergus and Newtownabbey

028 7034 3084 - CMHTOP Causeway

### **Occupational Therapy**

Occupational Therapists are health and social care professionals who help people to keep up their everyday activities and remain independent for as long as is possible. The service will usually complete an assessment in the person's own home environment and together work out possible solutions to overcome any difficulties the person may be having.

 028 70343 084 - Causeway area

028 94413 463 - Antrim, Ballymena, Mid Ulster and East Antrim

### **Dementia Home Support Team**

The Dementia Home Support Team provide behavioural assessment of individuals with dementia.

 028 94416 500

### **Sensory Support Service**

 [sensorysupport@northerntrust.hscni.net](mailto:sensorysupport@northerntrust.hscni.net)

 02825 863800

 Wilson House, 17 Raceview Rd, Broughshane, BT42 4JL

## **South Eastern Health and Social Care Trust**

### **Dementia Navigators**

Barbara Canning (Lisburn)

 028 9598 8098

 [barbara.canning@setrust.hscni.net](mailto:barbara.canning@setrust.hscni.net)

Francis McConnell (Lisburn)

 028 9598 8098

 [francis.mcconnell@setrust.hscni.net](mailto:francis.mcconnell@setrust.hscni.net)

Jenny Moran (North Down and Ards)

 028 9598 8098

 [jenny.moran@setrust.hscni.net](mailto:jenny.moran@setrust.hscni.net)

Linda Dornan (Downpatrick)

 028 9598 8098

 [linda.dornan@setrust.hscni.net](mailto:linda.dornan@setrust.hscni.net)

### **Mental health and older people's services**

The Mental Health Services of Older People team sits within the Department of Psychiatry for Old Age. The team cares for people of all ages with a dementia diagnosis or suspected dementia and people over 65 years of age with mental health difficulties.

 <https://setrust.hscni.net/service/mental-health-services-for-older-people/>

 028 9598 8098

### **Department of psychiatry for old age**

Consultant led, this is where memory assessments and diagnosis are carried out. Referrals from GPs or other health professionals.

### **District Nursing and older people's services**

 <https://setrust.hscni.net/?s=dementia+services>

 028 9598 8098

### **Sensory Support Service**

 028 9151 0136

 52 Church St, Newtownards, BT23 4AL

 028 446 16915

 Disability Resource Centre, Downshire Estate, Ardglass Rd, Downpatrick, BT30 6RA

 028 9260 774

 The Rowan Centre, 56 Wallace Avenue, Lisburn, BT27 4AE

## **Southern Health and Social Care Trust**

### **Dementia Co-ordinator**

Lindsay Porter

 [lindsay.porter@southerntrust.hscni.net](mailto:lindsay.porter@southerntrust.hscni.net)

### **Dementia Navigators**

Catherine McCorry (Trust wide - Under 65s)

 [catherine.mccorry@southerntrust.hscni.net](mailto:catherine.mccorry@southerntrust.hscni.net)

 028 3833 3332

Sheena McSherry (Craigavon and Banbridge - Over 65s)

 [sheena.mcsherry@southerntrust.hscni.net](mailto:sheena.mcsherry@southerntrust.hscni.net)

 028 3833 3332

Stephanie McGrory (Newry and Mourne - Over 65s)

 [stephanie.mcgrory@southerntrust.hscni.net](mailto:stephanie.mcgrory@southerntrust.hscni.net)

 028 3083 6970

Lucy Downey (Armagh and Dungannon - Over 65s)

 [lucy.downey@southerntrust.hscni.net](mailto:lucy.downey@southerntrust.hscni.net)

 028 3756 4957

## **Mental health and older people's services**

### **Integrated Care Teams**

The Southern Trust has three Integrated Care Teams - one in each geographical area of the trust. These teams are for anyone aged 65 or over, or anyone with dementia. These teams support in a

range of areas, including Day Care, Domiciliary Care, Occupational Therapy, Community/District Nursing.

 [access.information@southerntrust.hscni.net](mailto:access.information@southerntrust.hscni.net)

 <https://southerntrust.hscni.net/health-wellbeing/community-development-and-user-involvement/service-referrals-for-over-65s/>

<https://southerntrust.hscni.net/services/older-people-services/>

 028 3756 4300

### **Memory/Dementia Service Community Team**

Available for anyone whose dementia has progressed to be moderate or severe. The service provides a specialist, holistic, multi-disciplinary response for those people who experience memory difficulties, irrespective of age. The services are offered by a team of practitioners from medicine, mental health nursing, social work, and Allied Health Professions backgrounds that specialise in the area of dementia care.

 <https://southerntrust.hscni.net/service/memory-dementia-service/>

 028 3756 4300 / 028 3839 8335 (Memory Clinic)

### **Sensory Team**

 02838 394088 / (Mob) 07834929124

 Cherrytrees Resource Centre, 1A Edenderry Gardens, Craigavon, BT63 5EA

 02837 564444 / (Mob) 07919103501

 Jackson Hall, Main Building, St Lukes Hospital, Loughall Rd, Armagh, BT61 7NQ

## **Western Health and Social Care Trust**

### **Dementia Navigators**

Stephanie Coyle (Derry/Londonderry, Limavady and Strabane)

 [stephanie.coyle@westerntrust.hscni.net](mailto:stephanie.coyle@westerntrust.hscni.net)

 028 7186 4384 / 07920087601

Dementia Navigator (Omagh and Fermanagh)

 075 8599 8890

### **Dementia and Older People's Community Mental Health Services**

The dementia and Older People's Mental Health Team provides an assessment, treatment and support service for people aged over 65 with mental health problems, and all adults with dementia.

 <https://westerntrust.hscni.net/service/dementia-services/>

[https://westerntrust.hscni.net/wpfd\\_file/dementia-services/](https://westerntrust.hscni.net/wpfd_file/dementia-services/)

 028 7186 4384

### **Sensory Support Services**

 02871 320167 / (Mob) 07796448367

 Old Bridge House, Glendermott Rd, Londonderry, BT47 6AU

## **3.7 Types of services**

There are a number of services available and accessing them can be quite a complex process. We recommend that you speak to an adviser (for contact details see section 6)

### **Day Centres**

Day Care services aim to enable older people to live independently for as long as possible. Access to day care centres is by referral, usually through a GP, social worker, Community Psychiatric Nurse, district nurse and self-referral. Places are allocated following assessment and on the basis of need, subject to the regional access criteria. Day care is a regulated service. The RQIA carry out annual inspections and reports are available.

A list of all Day Centres in Northern Ireland is provided by the RQIA via this link:

 [https://rqia.org.uk/what-we-do/register/services-registered-with-rqia/Day Centres](https://rqia.org.uk/what-we-do/register/services-registered-with-rqia/Day_Centres)

### **Domiciliary/Home Care**

Domiciliary care is also known as Home Care. This is when carers or a personal assistant comes into the home to help with everyday tasks, enabling a person to remain independent in their own home for as long as possible. Home care is a regulated service. The RQIA carry out annual inspections and reports are available.

A list of all registered Domiciliary/Home care providers are included in this link:

 <https://rqia.org.uk/what-we-do/register/services-registered-with-rqia/>

### **Belfast Trust**

 <https://belfasttrust.hscni.net/service/homecare-home-help/>

### **Northern Trust**

 <http://www.northerntrust.hscni.net/services/domiciliary-care/>

### **South East Trust**

 <https://setrust.hscni.net/service/mental-health-services-for-older-people/>

### **Southern Trust**

 <https://southerntrust.hscni.net/service/domiciliary-care-home-help-service/>

### **Western Trust**

 <https://westerntrust.hscni.net/service/homecare-services/>

## **Residential/Nursing Homes**

Choosing a Residential or Nursing Home for your loved one can be a daunting task. Try to speak to your GP or social worker engaged with the person you are supporting with dementia. The following websites are also a useful source of information, and you can contact the organisations in the Advice and Advocacy section for information and advice.

A list of all Care Homes in Northern Ireland is provided by the Regulation and Quality Improvement Authority (RQIA)

 <https://rqia.org.uk/what-we-do/register/services-registered-with-rqia/rqia-register/nursing-homes/>

**Care Home UK** also provide a list of Nursing Homes

 [https://www.carehome.co.uk/care\\_search\\_results.cfm/searchcountry/Northern-Ireland/searchctype/alzheimers-and-dementia](https://www.carehome.co.uk/care_search_results.cfm/searchcountry/Northern-Ireland/searchctype/alzheimers-and-dementia)

**RQIA** have also produced a video

 <https://rqia.org.uk/guidance/guidance-for-the-public/choosing-a-care-home-video/>

**NI Direct** website on choosing a care home

 <https://www.nidirect.gov.uk/articles/choosing-residential-care-or-nursing-home>

**Age NI** also provide information on Care Homes

 <https://www.ageuk.org.uk/northern-ireland/information-advice/care/care-homes/>

as do the **Relatives and Residents Association**

 <https://www.relres.org/index.php>

The Department of Health provides information about care partner arrangements – your rights as a carer to be part of the care provided in a care or nursing home

 <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-care-partner-leaf-leaflet.pdf>

## Respite Care / Carer Break

Respite care or carer's break are the terms used for support services which enable you to take a break from caring. You can discuss this care with your Health and Social Care Trust, which is responsible for helping you to find different types of respite care or carer break. The person availing of the break may have to contribute to the cost. A person can also choose to arrange respite care without any help from the Health Trust. In this case, it is the person's responsibility to find and arrange the care.

### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/care/helping-a-loved-one/getting-support-and-looking-after-yourself/>

### Alzheimer's Society

 <https://www.alzheimers.org.uk/get-support/help-with-dementia-care/respice-care-northern-ireland>

### Carers N

 [https://www.carersuk.org/images/Factsheets/Taking\\_a\\_break\\_April\\_2019.pdf](https://www.carersuk.org/images/Factsheets/Taking_a_break_April_2019.pdf)

### Marie Curie

 <https://www.mariecurie.org.uk/help/support/being-there/support-carers/respice-care>

## Towards the end of Life

There are many different stages of the journey for a carer for someone living with dementia. Each person's experience is different. The journey usually begins long before diagnosis; through to decisions regarding the best care, and important life choices for carers and the person living with dementia; the different stages of deterioration, including Do Not Resuscitate (DNR) decisions. DNR needs to be considered with the person with dementia (if possible) and the wider family.

We've included this section on end of Life and when someone dies, not to scare you but to be honest. We often don't talk about death. Dementia is a palliative condition. Carers of people with dementia may experience a range of emotions including living grief (a sense of loss when the person is still alive but no longer able to have the same relationship with you) as well as actual grief and bereavement when the person you care for dies. Many carers experience these challenges and as such, they should be acknowledged.

### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/health-wellbeing/relationships-family/end-of-life-issues/>

<https://www.ageuk.org.uk/northern-ireland/information-advice/health-wellbeing/relationships-family/end-of-life-issues/>

### Alzheimer's Society

 <https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care>

## **Marie Curie**

 <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/dementia>

## **Northern Ireland Hospice**

 <https://www.nihospice.org/adult-hospice/adult-hospice-services/for-families-and-carers/bereavement-care>

## **Grief and Bereavement**

Losing someone close to you can be devastating. If you have been caring for that person, the loss can seem even greater. How you cope with the death of the person you cared for is a very individual thing. There is no right or wrong way to feel following a death. In addition to the emotional impact, there are also practical issues to think about after a person dies. Though you may find it difficult, it is important that you or someone else think about the following: registering the death, funeral plans and changes to financial and legal documents and benefits.

## **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/help-dementia-care/grief-loss-and-bereavement>

## **Carers NI**

 <https://www.carersuk.org/files/section/5042/factsheet-ni1032-when-caring-ends-or-changes-web.pdf>

## **Cruse Bereavement Care**

 <https://www.cruse.org.uk>

[https://www.cruse.org.uk/sites/default/files/default\\_images/pdf/Areas/Waies/Dementia%20brochure%20English%20%282%29.pdf](https://www.cruse.org.uk/sites/default/files/default_images/pdf/Areas/Waies/Dementia%20brochure%20English%20%282%29.pdf)

 028 9043 4600 / 0808 808 1677

## **Life after caring**

Carers may be grieving but also have a gap in their lives which their many caring duties occupied. The following organisations can provide support and help.

## **Carers NI**

 <https://www.carersni.org/information/whencaringends/lifeaftercaring>

## **Cruse Bereavement Care**

 <https://www.cruse.org.uk>

 028 9043 4600 / 0808 808 1677

And of course – tide (our details are in the introduction and on the back of this handbook).

### 3.8 Overall Health and Social Care information sources

#### Health and Social Care Board

The Health and Social Care Board (HSCB) is a statutory organisation. It arranges or 'commissions' health and social care services for the population of Northern Ireland.

✉ [enquiry.hscb@hscni.net](mailto:enquiry.hscb@hscni.net)

🌐 <http://www.hscboard.hscni.net/our-work/social-care-and-children/getting-help-for-carers/>

📞 0300 555 0155

✉ 12-22 Linenhall Street, Belfast BT2 8BS

📘 @healthandsocialcareboard

🐦 @HSCBoard

The dementia site has information about a range of developments that may be of interest to carers relating to planning for dementia and carers.

🌐 <http://www.hscboard.hscni.net/?s=dementia>

There are also a range of guides published by Dementia Together project

🌐 <https://www.publichealth.hscni.net/publications?keys=dementia> and <https://www.publichealth.hscni.net/publications?keys=delirium>

The Health and Social Care Board have partnered with ORCHA (Organisation for the Review of Care and Health Applications) to set up a website: **Apps 4 dementia**. The website includes top-rated apps on issues including Information and Guidance, Active Minds, Staying Calm and Sleeping Well, Carer Support, Communication and Memories.

🌐 <https://apps4dementia.orchaco.uk/about/>

#### Department of Health

The Department of Health is one of nine government departments in the NI Executive. The Department has responsibility for all aspects of health and social care, public health and public safety in Northern Ireland. This includes hospitals, family practitioners services, community health and social services. Dental, pharmaceutical, nursing and allied health professionals (like physiotherapists) services are also included.

✉ [webmaster@health-ni.gov.uk](mailto:webmaster@health-ni.gov.uk)

🌐 <https://www.health-ni.gov.uk>

📞 028 9052 0500

✉ Castle Buildings, Stormont, Belfast, BT4 3SQ

🐦 @healthdpt

## **NI Direct**

The NI Direct website has information on signs of dementia, living well with dementia and supporting someone with dementia as well as help and support information.

 [www.NIDirect.gov.uk/dementia](http://www.NIDirect.gov.uk/dementia)

## **Public Health Agency**

The Public Health Agency is a regional statutory organisation with a focus on health protection, health and social wellbeing improvement, and prevention and health inequalities.

 <https://www.publichealth.hscni.net>

<https://www.publichealth.hscni.net/search/node?keys=dementiawebmaster@health-ni.gov.uk>

 0300 555 0114

 12-22 Linenhall St, Belfast BT2 8BS

 @publichealthagency

 @publichealthni

## 4 Financial and Legal Issues

As the carer of someone living with dementia, there are a range of financial and legal issues that you and/or they will have to consider. While it might be difficult, it is a good idea to plan ahead and look into these matters sooner rather than later. And it is recommended that you seek professional advice, as some aspects are quite complex.

It is a good idea for the person with dementia to get all their official paperwork in order as early as possible. This can include things like bank/building society/credit union accounts; mortgage or rent details - and where deeds of house(s) are kept if property is mortgage free; life insurance policies; private health insurance policies; benefits/pensions/tax details; utility bills; investments; Enduring Power of Attorney and a will - if there is one.

If the person living with dementia still has the ability to make decisions for themselves (known as **mental capacity**), it is advisable to take steps to get their financial and legal affairs in order while they still can. This can make it easier for them and you to manage things as their dementia progresses. It also means they will get to decide how their affairs will be managed in the future, and who will do this. And it can make things easier for carers and other loved ones.

If you are caring for someone who no longer can make decisions for themselves (lacks mental capacity), then a number of alternative processes become necessary (see below).

For an overview on financial and legal matters, go to the following websites:

### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/money-matters/legal-issues/>

### Alzheimer's Society

 [https://www.alzheimers.org.uk/sites/default/files/2020-03/financial\\_and\\_legal\\_tips\\_ni467.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-03/financial_and_legal_tips_ni467.pdf)

### 4.1 Financial matters

While it may seem a bit artificial to separate financial from legal matters, as both can often overlap, we've divided them here in an attempt to simplify the key areas for you to consider:

- Bank/building society/credit union accounts
- Savings/investments
- Debts
- Financial planning
- Tax issues
- Benefits

### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/money-matters/>

<https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/more-money-in-your-pocket-2019-web-version.pdf>

## **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/legal-financial/where-financial-legal-advice-northern-ireland>

<https://www.alzheimers.org.uk/get-support/legal-financial/benefits-dementia>

<https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-managing-money>

## **Money Advice Service**

Money Advice Service is a government-funded service that can give you information about a range of financial issues.

 enquiries@maps.org.uk

 www.moneyadviceservice.org.uk

 0800 138 7777

## **Paying for care**

As a carer of someone living with dementia, you may have to organise care for them at home, arrange some home adaptations or explore the possibility of a care home. Paying for care can be a worrying issue. We recommend that you speak to an independent adviser as early as possible. Having the right information and support can really help you to navigate your way through these systems and processes. We have included a number of information sites below which you might find useful. A list of advice organisations is included in section 6.

## **Age NI**

 [https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age\\_ni\\_guide\\_care\\_homes.pdf](https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age_ni_guide_care_homes.pdf)

<https://www.ageuk.org.uk/northern-ireland/information-advice/care/social-care-and-support-where-to-start/>

<https://www.ageuk.org.uk/northern-ireland/information-advice/care/social-care-and-support-where-to-start/paying-for-care-support/>

## **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/legal-financial/paying-dementia-care-support-northern-ireland>

## 4.2 Legal matters

These include various issues such as:

- Enduring Power of Attorney (EPA)
- Making a will
- Trusts
- Advance planning for care and treatment
- Controllership (if no Enduring Power of Attorney exists)

### Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is a legal document which can be set up by the person with dementia that you are caring for. It allows someone to make decisions, or act on their behalf, if the person is no longer able to make their own decisions.

It must be set up and registered before it is needed - while the person is capable of making their own decisions and have 'mental capacity'. Through the EPA the person (called the 'donor') appoints someone to manage their property and financial affairs (called 'attorney'). Once an EPA has been registered, it can be used at any time, including if you lose your mental capacity.

### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/money-matters/legal-issues/power-of-attorney/>

### Alzheimer's Society

 <https://www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney-northern-ireland>

<https://www.alzheimers.org.uk/law-northern-ireland>

### Department of Justice

 <https://www.justice-ni.gov.uk/publications/epa-notes-and-forms>

### Law Society of Northern Ireland

 <https://www.lawsoc-ni.org/publications.aspx>

### Which? Magazine

 <https://www.which.co.uk/late-life-care/financing-care/organising-financial-affairs/power-of-attorney-in-northern-ireland-anbs40m5v25m>

### Making a will

In terms of planning ahead, making a will is an important step for the person living with dementia. It ensures that the people they want will benefit from their property and possessions (called the 'estate') after they die. It can also help ensure that the person doesn't pay more Inheritance Tax than they need to. If the person does not make a will their estate will be passed on through

Intestacy Rules and who is entitled under this scheme will depend on which relatives survive the deceased person.

It is generally a good idea to seek the advice of a solicitor who specialises in wills and probate before making a will. The Law Society of Northern Ireland provides a list of solicitors. Solicitors will usually ask for a medical opinion when a person with a dementia diagnosis makes a will.

### **Age NI**

 <https://www.ageni.org/wills>

[https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age\\_ni\\_wills\\_guide.pdf](https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age_ni_wills_guide.pdf)

### **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together-magazine/can-someone-dementia-make-will>

## **Trusts**

A Trust is a way of looking after assets for other people, for example when someone is too young to manage their affairs. If anyone under the age of 18 is to be a beneficiary of the trust, then the person making the trust should appoint at least two trustees or executors. Take professional advice around creating a trust.

## **Advance planning for your care and treatment**

**Advance Care Plans** sets out the person's wishes about how they would like to be cared for at the end of their life.

### **Advance Decisions to Refuse Treatment (Advance Directives)**

An Advance Directive records the person with dementia's decisions about future medical care. It is a legal document that allows the person to refuse, in advance, specific medical treatments or procedures – for example, whether to be resuscitated if your heart stops. It cannot be used to refuse basic care.

### **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/staying-independent/planning-future-dementia-care>

### **MacMillian Cancer Support**

 <https://www.macmillan.org.uk/information-and-support/oesophageal-gullet-cancer/organising/advanced-cancer-planning/advance-care-planning-northern-ireland>

## **Controllership - If the person you are caring for lacks mental capacity**

If the person with dementia that you are caring for is no longer able to make their own decisions, legally it is too late to apply for an Enduring Power of Attorney. In this situation, if there is no valid

Enduring Power of Attorney, you (or someone else) need to make an application for a 'Controllership Order' to the Office of Care and Protection. Anyone can apply for such an order, including a partner, family member, friend or a professional, such as a solicitor, or someone from the person's local authority social work department.

A Controllership Order authorises the Controller to do anything that appears necessary or expedient with respect to the property and financial affairs of the person lacking capacity. The person appointed under controllership has to report regularly and are monitored by the Office of Care and Protection in relation to all actions and decisions they've taken in relation to the financial affairs of the person with dementia.

### **Office of Care and Protection**

 [epa@courtsni.gov.uk](mailto:epa@courtsni.gov.uk)

 <https://www.justice-ni.gov.uk/topics/courts-and-tribunals/office-care-and-protection-patients-section>

 0300 200 7812

 The Office of Care and Protection Room 2.02, First Floor Royal Courts of Justice, Chichester Street, Belfast, BT1 3JF

## 5 Entitlements - benefits and assessment information sources

As a carer or someone living with dementia, you may be entitled to some benefits. The rules on eligibility are complex. There are a number of organisations which provide independent information, advice and support, and we have included a list below. We have also included a list of the benefits you may be entitled to with links for further information and contact details of relevant departments.

### 5.1 Benefits you may be entitled to

There are a number of benefits that carers or people living with dementia may be entitled to. These include, but are not limited to:

- Attendance Allowance (AA)
- Carers Allowance (CA)
- Disability Living Allowance (DLA)
- Employment & Support Allowance (ESA)
- Housing Benefit (HB)
- Jobseekers Allowance (JSA)
- Pension Credit (PC)
- Personal Independence Payment (PIP)
- Universal Credit (UC)

### 5.2 Assessments you or the person with dementia you are caring for may be entitled to

Social services can assess your needs and those of the person with dementia that you are caring for. You can find out more about assessments via the links below and also via your local health and social care trust.

#### Carer's Assessment

As a carer you have a right to a Carer's Assessment, but you have to ask for it. Social services should tell you about your right to a Carer's Assessment, but it is important to remember that you will still need to ask them to carry out an assessment for you.

A carer's assessment is for people who provide 'regular and substantial' care for someone such as a partner, friend or relative. You can have a carer's assessment whether or not the person you care for has had a community care assessment or wants one themselves. Following the assessment, you will be given information about services and support you can be eligible for. You may self refer by contacting the Social Services team in your area; be referred by a GP or someone who works for the Health Trust; by a voluntary organisation; or by a family member or an informal carer.

#### Age NI

 <https://www.ageuk.org.uk/northern-ireland/information-advice/care/helping-a-loved-one/can-carers-get-help-from-social-services/>

#### Alzheimer's Society

 <https://www.alzheimers.org.uk/get-support/legal-financial/carers-assessments-northern-ireland>

## **Carers NI**

 [carersuk.org/carersassessment](https://carersuk.org/carersassessment)

## **Marie Curie**

 <https://www.mariecurie.org.uk/help/support/being-there/support-carers/assessments>

## **Care Needs Assessment**

Your local Health and Social Care Trust has a duty to assess the care needs of the person with dementia that you are caring for. This care needs assessment will allow the Trust to determine what supports the person living with dementia needs. It will also help them to determine what if any financial contribution the Trust will make towards meeting the costs of these services. You do not have to wait until the person you are caring for has received a diagnosis.

It is important to know that the HSC Trust does not have a duty to arrange services unless an assessment has taken place, so it's important to get an assessment. You may self refer by contacting the Social Services team in your area; be referred by a GP or someone who works for the Health Trust; by a voluntary organisation; or by a family member or informal carer.

## **Age NI**

 [https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age\\_ni\\_guide\\_care\\_at\\_home.pdf](https://www.ageuk.org.uk/globalassets/age-ni/documents/advice/age_ni_guide_care_at_home.pdf)  
<https://www.ageuk.org.uk/northern-ireland/information-advice/care/social-care-and-support-where-to-start/care-needs-assessment/>

## **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/legal-financial/assessment-care-support-northern-ireland#content-start>

## **Marie Curie**

 <https://www.mariecurie.org.uk/help/support/terminal-illness/care-needs/social-care>

## **Direct Payments**

A direct payment is an amount of money paid directly to the person with dementia by the Health and Social Care Trust, to pay for their care and support. This option is only available after the Trust has found the person eligible following a care needs assessment. You can find out further details on the websites below and also by calling any of the advice organisations listed below.

## **Age NI**

 <https://www.ageuk.org.uk/northern-ireland/information-advice/care/social-care-and-support-where-to-start/personal-budgets-and-direct-payments/>

## **Alzheimer's Society**

 <https://www.alzheimers.org.uk/get-support/legal-financial/northern-ireland-personal-budgets>

## 6 Advice and Advocacy Services

There is a lot of information about dementia and separate information available about carers. In addition, some of this information can be quite complicated. Given the volume and complexity of the information, it can be easy to feel overwhelmed, which is why we strongly suggest that you seek advice and support to help you through your journey.

We have listed a range of useful organisations below and given a little bit of information about them, in order that you can find the best ones to meet your needs. The information in the websites directly below give detail about the types of advice available in Northern Ireland. It is very helpful and we suggest that you read this or speak to the organisations directly.

### 6.1 Free independent advice (including legal and financial advice on a range of issues)

#### Advice NI

Advice NI co-ordinate the Independent Advice Network, with expert advice available locally across Northern Ireland through a network of independence advice centres. They provide advice on a wide range of issues, including benefits, debt, including business debt.

 [advice@adviceni.net](mailto:advice@adviceni.net)

 <https://www.adviceni.net>

 0800 915 4604 (Helpline) / Text: ACTION to 81025

 Forestview, Purdy's Lane, Newtownbreda, Belfast, BT8 7AR

 @AdviceNI

 @AdviceNI

#### Age NI

Advice and Advocacy Service

 [advice@ageni.org](mailto:advice@ageni.org)

 <https://www.ageuk.org.uk/northern-ireland/services/advice-advocacy/>

 0808 808 7575

 3 Lower Crescent, Belfast, BT2 7NR

 @Age\_NI

 @agenicharity

#### Alzheimer's Society

There are carer support groups running in some areas and an online forum for carers called Talking Point. They offer a wide range of very informative Factsheets available on their website.

 [nir@alzheimers.org.uk](mailto:nir@alzheimers.org.uk)

 <https://www.alzheimers.org.uk/about-us/northern-ireland>  
 028 9066 4100 / 0300 222 11 22 (Dementia Connect Helpline)  
 @AlzheimersSocietyNorthernIreland  
 @AlzSocNI

### **Carers NI**

Carers NI provides an enquiry service for carers and professionals.

 [advice@carersni.org](mailto:advice@carersni.org)  
 <https://www.carersuk.org/northernireland>  
 028 90439843  
 58 Howard Street, Belfast BT1 6PJ  
 @CarersNI  
 @CarersNI

### **Centre for Independent Living NI**

The Centre for Independent Living provides information and advice on getting direct payments, using personal budgets and employing carers and personal assistants.

 [info@cilbelfast.org](mailto:info@cilbelfast.org)  
 [www.cilbelfast.org](http://www.cilbelfast.org)  
 028 9064 8546 / Text Phone 028 9064 0598  
 Beechill Business Park, 96 Beechill Road, Belfast, BT8 7QN  
 @centreforindependentlivingni  
 @cfilni

### **Citizen's Advice Bureau**

Citizen's Advice Bureau has a number of independent advice agencies across Northern Ireland, operating under different names, which provide independent confidential advice by phone or in person. They also provide advice on consumer and pension issues.

Address: See website for your nearest branch.

 [www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)  
 0300 123 3233

### **Law Centre NI**

The Law Centre (NI) is a not for profit organization which supports the work of advice sector organisations. The areas of work dealt with are social security, employment and immigration. If the Law Centre is not able to assist you directly, they will try to refer you to an organisation that can.

 [admin@lawcentreni.org](mailto:admin@lawcentreni.org)

 [www.lawcentreni.org](http://www.lawcentreni.org)

 028 9024 4401

 2<sup>nd</sup> Floor, Westgate House, 2-4 Queens Street, Belfast BT1 6ED

 @LawCentreNI

 @LawCentreNI

### **Marie Curie**

Provides frontline nursing and hospice care, a free support line and information and support on all aspects of dying, death and bereavement.

 <https://www.mariecurie.org.uk/help/support/benefits-entitlements>

 0800 090 2309 / 028 9433 1868 (Northern Ireland Switchboard)

 1A Kensington Road, Belfast BT5 6NF

 @MarieCurieNorthernIreland

 @MarieCurieNI

## **6.1 Financial advice**

If you or the person you are caring for need advice about savings or investments, you may need to seek professional financial advice.

### **Money Advice Service**

The Money Advice Service has information about the different types of financial adviser and how to go about finding one. Keep in mind that some advisers can only advise on a restricted range of products. An independent adviser can advise you on a wider range of products. All financial advisers must be approved by the Financial Conduct Authority (FCA).

You may wish to speak to several advisers before making up your mind. Check before you make an appointment, on how you will be charged and if the initial conversation is free.

 [enquiries@maps.org.uk](mailto:enquiries@maps.org.uk)

 [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)

 0800 138 7777

 @YourMoneyAdvice

### **Financial Conduct Authority**

The Financial Conduct Authority regulates financial advisers and provides information about what to do if you have a complaint.

 [consumer.queries@fca.org.uk](mailto:consumer.queries@fca.org.uk)

 [www.fca.org.uk](http://www.fca.org.uk)

 0800 111 6768

 @The FCA

## 6.2 Legal advice

If you are dealing with legal issues, such as making an Enduring Power of Attorney or a will, or controllership, it can be a good idea to talk to a solicitor.

The independent advice/law centre organisations provide free advice on some legal issues – it may be worth contacting them to find out if they can advise on the query that you have. (For a list of these organisations, see section 6). If you are a member of a Trade Union, you may be eligible for free legal advice on matters beyond employment law. It may be worth getting in touch with them to find out.

### Law Society of Northern Ireland

The Law Society of Northern Ireland can help you find a solicitor. You may wish to call around and speak to a few solicitors before making a decision. As part of that, always check how you will be charged before you make an appointment with a solicitor, and how much their fee will be. It is advisable to get this in writing.

 <https://www.lawsoc-ni.org/publications.aspx>

 028 9023 1614

 96 Victoria Street, Belfast, BT1 3GN

 @LawSociety\_NI

### Legal Services Agency Northern Ireland (LSANI)

 [enquiries@lsani.gov.uk](mailto:enquiries@lsani.gov.uk)

 [www.lsani.gov.uk](http://www.lsani.gov.uk)

<https://www.justice-ni.gov.uk/topics/legal-aid/legal-services-agency-northern-ireland>

 028 9040 8888

 2<sup>nd</sup> Floor, Waterfront Plaza, 8 Laganbank Road, Belfast, BT1 3BN

## 7 Human rights/Commissions/Regulators

At this time we believe that carers have human rights and these should be recognised. A rights based framework would help to ensure public services, and policies are developed which properly recognise, identify and support carers.

### The Human Rights of Carers

This research paper is designed to offer a practical approach by setting out the main human rights laws alongside key domestic legislative and policy provision.

 [https://nihrc.org/uploads/publications/The Human Rights of Carers.pdf](https://nihrc.org/uploads/publications/The_Human_Rights_of_Carers.pdf)

### Commissioner for Older People for Northern Ireland

The Commissioner for Older People (COPNI) can provide advice and information to older people, defined as anyone aged 60 or over.

 [info@copni.org](mailto:info@copni.org)

 [www.copni.org](http://www.copni.org)

 028 9089 0892

 Equality House, 7-9 Shaftesbury Square, Belfast, BT2 7DP

 @COPNI2011

 @COPNI

### Equality Commission for Northern Ireland

An independent public body which oversees equality and discrimination laws in Northern Ireland. If you need information or think you have been discriminated in terms of accessing a service.

 [information@equalityni.org](mailto:information@equalityni.org)

 [www.equalityni.org/Home](http://www.equalityni.org/Home)

 028 90 500 600

 Equality House, 7-9 Shaftesbury Square, Belfast, BT2 7DP

 @EqualityCommNI

 @EqualityCommNI

### Northern Ireland Commissioner for Complaints – Office of the Northern Ireland Public Services Ombudsman

The Ombudsman deals with complaints against public services. Usually, before you complain to the Ombudsman about the service you or the person you are caring for, you will be expected to have exhausted the organisation's internal complaints procedure. If you are unhappy with how your

complaint has been dealt with, you can refer your complaint to this Ombudsman. They will look at your complaint and decide whether s/he should investigate.

 [www.ni-ombudsman.org.uk](http://www.ni-ombudsman.org.uk)

 0800 343 424

 Freepost RTKS-BAJU-ALEZ Belfast BT1 6BR

 @NIPSO\_Comms

### **Northern Ireland Human Rights Commission**

An independent organisation to make sure the government and other public bodies protect the human rights of everybody in Northern Ireland. The Commission provides legal information and advice, including taking strategic legal cases.

 [info@nihrc.org](mailto:info@nihrc.org)

 [www.nihrc.org/about-us](http://www.nihrc.org/about-us)

 028 90243987

 4<sup>th</sup> Floor Alfred House, 19-21 Alfred Street, Belfast BY2 8ED

 @nihrc

 @NIHRC

### **Office of the Mental Health Champion**

Office of the Mental Health Champion was established in 2020 to to advise and assist in the promotion of mental health and wellbeing through all policies and services throughout Northern Ireland. The Mental health Champion is Professor Siobhan O'Neill.

 [MHC@hscni.net](mailto:MHC@hscni.net)

 [www.nidirect.gov.uk/contacts/contacts-az/office-mental-health-champion](http://www.nidirect.gov.uk/contacts/contacts-az/office-mental-health-champion)

 028 9536 8368

 @MHC\_NI

### **Patient and Client Council**

Set up to be an independent voice for patients, clients, carers and communities across Northern Ireland in Health and Social Care, the Patient and Client Council can support you if you have a concern or wish to make a complaint about any part of Health and Social Care.

 [www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)

 0800 917 0222

 5th floor, 14-16 Great Victoria Street, Belfast, BT2 7BA

 @PatientAndClientCouncil

 @PatientClient

## 8 Other Government departments and agencies

Specific information on dementia and carers in NI Direct and Health and Social Care sites are detailed in section 3: Dementia specific services Health and Social Care and Trust-led

### Health Minister, Robin Swann MLA

@ [webmaster@health-ni.gov.uk](mailto:webmaster@health-ni.gov.uk)

<https://www.health-ni.gov.uk>

028 9052 0500

Department of Health, Castle Buildings, Stormont, Belfast, BT4 3SQ

@heatlhdp

### Justice Minister, Naomi Long MLA

@ [dojweb@justice-ni.x.gsi.gov.uk](mailto:dojweb@justice-ni.x.gsi.gov.uk)

<https://www.justice-ni.gov.uk>

028 9076 3000 / **Textphone:** (028) 9052 7668

Department of Justice, Block B, Castle Buildings, Stormont, Belfast, BT4 3SG

@Justice\_NI

### NI Assembly: Find your MLA

<http://aims.niassembly.gov.uk/mlas/locatemla.aspx>

### Make the Call - Government run advice line

<https://www.nidirect.gov.uk/contacts/contacts-az/benefit-enquiry-line>

[https://www.nidirect.gov.uk/campaigns/unclaimed-benefits?gclid=Cj0KCCQiAx9mABhD0ARIsAEfpavTHnOBpDc684Wc-4Pu8FoVDn-15Jthyws6peQmpEiVoWv1URTglzKYaAke2EALw\\_wcB](https://www.nidirect.gov.uk/campaigns/unclaimed-benefits?gclid=Cj0KCCQiAx9mABhD0ARIsAEfpavTHnOBpDc684Wc-4Pu8FoVDn-15Jthyws6peQmpEiVoWv1URTglzKYaAke2EALw_wcB)  
<https://www.nidirect.gov.uk/campaigns/guide-benefits>

800 232 1271

## 9 Relevant legislation and strategies

Some carers will be interested in the wider context of caring for someone with dementia. Below are some documents that may of interest if you'd like to know more:

### **Carers: Legislation, Policy and Practice**

A Research and Information Service Briefing Paper from the Northern Ireland Assembly. This paper looks at the provisions for supporting carers in law and policy across the UK; key issues for carers, with additional reference to wider EU work in this regard; and some particular examples of good practice in selected EU countries (published in 2016.)

 [Carers: Legislation, Policy and Practice \(niassembly.gov.uk\)](https://niassembly.gov.uk)

### **Carer's Strategy**

The strategy sets out what we have been doing and a vision of what still needs to be done to give carers the quality of life we believe they deserve. The basic rights of carers to accessible information, employment and training opportunities, and stronger support networks are addressed through this strategy (published 2006.)

 [Caring for carers | Department of Health \(health-ni.gov.uk\)](https://health-ni.gov.uk)

### **Improving Dementia Services in Northern Ireland: a regional strategy**

The dementia strategy will attempt to reduce the risk or delay the onset of dementia in the population; it has been estimated that delaying the onset of dementia by five years could halve its prevalence (published 2011.)

 [Improving dementia services in Northern Ireland - a regional strategy | Department of Health \(health-ni.gov.uk\)](https://health-ni.gov.uk)

### **Regional Dementia Care Pathway**

This aims to improve the services and support arrangements currently available for people with dementia, their families and carers.

 [Dementia Care Pathway Book.pdf \(hscni.net\)](https://hscni.net)

### **The Mental Capacity Act**

The Mental Capacity Act (NI) 2016 ("the Act") is legislation that will fuse together mental capacity and mental health law for those aged 16 years old and over within a single piece of legislation, as recommended by the Bamford Review of Mental Health and Learning Disability. The Act provides a statutory framework for people who lack capacity to make a decision for themselves and for those who now have capacity but wish to make preparations for a time in the future when they lack capacity.

 [www.health-ni.gov.uk/mca](https://www.health-ni.gov.uk/mca)

## 10 Other support organisations

### Action on Elder Abuse.

 080 8808 8141

### Alcoholics Anonymous

 [csoofaa@btconnect.com](mailto:csoofaa@btconnect.com)

 [www.alcoholicsanonymous.ie](http://www.alcoholicsanonymous.ie)

 028 9043 4848

 7 Donegall Place, Belfast, BT1 2FN

### British Deaf Association

 <https://bda.org.uk/belfast-office>

 028 9043 7480 / Text/FaceTime: 07795 410724

 Weaver's Court, Unit 5c, Linfield Road, Belfast, BT12 5

 @BritishDeafAssociation.NorthernIreland

 @BDA\_Deaf

### Chinese Welfare Association

 [office@cwa-ni.org](mailto:office@cwa-ni.org)

 <https://www.cwa-ni.org/about/#>

 028-90288277

 1 Stranmillis Embankment, Belfast, BT7 1GB

### Digital Help

Text the word DIGITALHELP (all one word) to 67300 with a brief description of what help you require.

 [www.nidirect.gov.uk/information-and-services/go-ni/events-and-training](http://www.nidirect.gov.uk/information-and-services/go-ni/events-and-training)

Help with Digital Devices: <https://supportingcommunities.org/latest-events/2021/1/7/get-to-know-your-new-device>

### Disability Action

 [information@disabilityaction.org](mailto:information@disabilityaction.org)

 [www.disabilityaction.org](http://www.disabilityaction.org)

 028 9029 7880

 Portside Business Park, 189 Airport Road West, Belfast, BT3 9ED

 @disabilityaction

 @disabilityni

### **HEReNI**

 [tracey.mcdowell@hereni.org](mailto:tracey.mcdowell@hereni.org)

 <https://here875008472.wordpress.com>

 028 9024 9452

 23-31 Waring Street, Belfast, BT1 2DX

### **Lifeline**

 0808 808 8000 / Textphone18001 0808 808 8000

### **Mencap NI**

 [www.northernireland.mencap.org.uk](http://www.northernireland.mencap.org.uk)

 028 9069 1351

 5 School Road, Castlereagh, Belfast, BT8 7US

 @Mencap\_NI

 @Mencap\_NI

### **Migrant Centre NI**

 [management@migrantcentreni.org](mailto:management@migrantcentreni.org)

 <http://migrantcentreni.org/>

### **Narcotics Anonymous**

 [contact@nanorthernireland.com](mailto:contact@nanorthernireland.com)

 [www.nanorthernireland.com](http://www.nanorthernireland.com)

 078 1017 2991

 P.O. Box 543, Tomb Street, Belfast, BT1 1AA

### **Northern Ireland Council for Racial Equality (NICRE)**

 [patrick@nicre.org](mailto:patrick@nicre.org)

 <https://nicre.org/services/>

 407710 767235

 7 Rugby Road, Belfast, BT7 1PS

### **The Rainbow Project**

 [www.rainbow-project.org](http://www.rainbow-project.org)

 028 9031 9030

 LGBT Centre, 23-31 Waring St, Belfast, BT1 2DX

 @TheRainbowProjectNI

 @TRPNI

### **Relate NI**

 [office@relateni.org](mailto:office@relateni.org)

 [www.relateni.org/contact](http://www.relateni.org/contact)

 028 9032 3454

 3rd & 4th Floors, 3 Glengall Street, Belfast, BT12 5AB

 @RelateNorthernIreland

 @RelateNI

### **Samaritans**

 [jo@samaritans.org](mailto:jo@samaritans.org)

 [www.samaritans.org](http://www.samaritans.org)

 028 9066 4422

 Thomson House, 5 Wellesley Avenue, Belfast, BT9 6DG

 @samaritanscharity

 @samaritans

### **Sense Northern Ireland**

 [nienquiries@sense.org.uk](mailto:nienquiries@sense.org.uk)

 [www.sense.org.uk](http://www.sense.org.uk)

 028 9083 3430 (inlc textphone)

 The Manor House, 51 Mallusk Road, Newtownabbey, BT36 4RU

 @sensecharity

**Women's Aid**

 0808 802 1414

 @WomensAidNI

 @WomensAidNI

## Carer to Carer – Cheat Sheets

As well as the organisations and information provided in this handbook we thought some advice from carer to carer would help. Some will be applicable to you now or in the future. Some of it may never be relevant. Please take what's useful and disregard the rest.

### Cheat Sheet: Initial diagnosis

- Speak to the GP of the person you are caring for – with the person who is living with dementia – to discuss your concerns and thoughts around their situation.
- Ask for a referral to the Memory Clinic
- Ask for a referral to the Dementia Navigator and local HSC dementia support services.
- Ask the GP to refer you to social services in order to get a Social Worker who can help guide you through certain processes.
- Ask your GP and local Health Trust to acknowledge your role as a carer. Being registered or the role noted on your records, as a carer can allow you certain benefits such as priority shopping and quicker access to vaccines etc. It also helps recognise the value of what you are doing and the contribution you make.
- Apply for a Blue Badge if you are a driver. The process is easy and allows you to access Disabled Parking spots. It can be very helpful whether you are still driving the person you are caring for, having to run messages or do shopping for them.
- Apply for Direct Payments, Carers Support or any other applicable grants and benefits that you may be eligible for. Our Handbook tells you how.
- Ask your GP or Social Worker to refer you for a Carers Assessment which can help to access you support of all kinds, if necessary.
- Speak to professionals about making a will if one does not exist.
- Put in place an Enduring Power of Attorney, to allow you to legally act on behalf of the person you are caring for. Without this, you have very limited rights to speak or act on their behalf.
- If you are caring for someone with a hearing or sight disability, connect with Sensory Support who are skilled in offering additional support, technical or living adjustments in the home.
- Speak to your family or friends to talk about your concerns and worries. Talk to them about how you can share responsibilities and caring duties.

**Remember, to be able to help others you must first look after yourself, mentally and physically. As a carer, this may sound selfish or not what you are used to doing. However, from other carers experience, we know that it is easy to become overwhelmed without realising. Taking 10 or 20 minutes regularly do something for you. This will help reenergise you and give you the strength to go on. Be kind to yourself.**

## Cheat Sheet: Domiciliary Care and help in the home

- If you need additional help in the home and caring for someone with Dementia you can ask your GP, Social Worker or the Health Trust involved to provide an agency. Otherwise you may be able to use Direct Payments to pay for additional help or hire an agency yourself.
- If you are hiring an agency, ask the health care professionals you work with to recommend a few. Look for agencies that are local to you as travel time can be an additional cost.
- Clarify costs and how care is charged – by hour or a daily rate? Are there extra charges for weekends and holidays (eg Bank Holidays, Easter or Christmas etc). Be clear on payment terms, notice periods and proposed schedules in advance.
- Consider if you need specifically male or female carers, though this may limit your choices.
- Establish if the agency is familiar with working with people living with dementia.
- You should detail out all of the tasks that need actioned such as help with getting dressed or getting in or out of bed, making the bed, washing, etc. This list will act as a Care Plan and needs to be agreed by you and the agency. Remember, what may seem obvious to you or need to be done may not be clear to someone else. If it's not in the Care Plan, it won't get done.
- If you are expecting them to cook or heat food, clarify what their procedure is, what they can and can't do and be clear on which food and drinks are acceptable and in what format. For example, drinks may need to be served with a straw, food may need to be soft and easily chewed or served as small portions.
- Specify if and how medication should be taken and where it is kept. You may need to get a locked box to secure medicine.
- Establish procedure for emergencies and who you should contact if there is a problem, how they are contacted and what happens 'out of hours' at the weekend or late at night.
- Be clear on how you should be contacted if there is an emergency and what you consider an emergency.
- Speak to your family or friends to talk about your concerns and worries. Talk to them about how you can share responsibilities and caring duties.

**Remember, to be able to help others you must first look after yourself, mentally and physically. As a carer, this may sound selfish or not what you are used to doing. However, from other carers experience, we know that it is easy to become overwhelmed without realising. Taking 10 or 20 minutes regularly to do something for you. This will help reenergise you and give you the strength to go on. Be kind to yourself.**

## Tide Carer Cheat Sheet: Choosing a Residential Care or Nursing Home

- The Regulation and Quality Improvement Authority (RQIA) is the regulatory body for Care Homes in Northern Ireland. They provide a guide to, and inspection reports on homes.
- Some homes are not able to care for people living with dementia. Other nursing homes are registered as dementia care homes providing specialised care but you need to check.
- Clarify who is paying for the home before you decide, what the fees cover and do not cover. Establish payment terms in advance. Costs can escalate quickly. Your social worker can advise.
- Think about what is important to you and the person you care for, in choosing a home. Location may impact how often you can visit, is a separate bedroom offered or are bedrooms shared, are there en-suite facilities, communal areas with space to enjoy activities?
- Ask friends, local support groups, your GP or social worker if they have experience of homes in your local area in order to get a feel for what suits you.
- Do a list of all belongings BEFORE entering the home and take photos if possible. Clothes and belongings often become lost. Keep a copy of the list and ask the home to note and agree what they have received. Labelling all items with name labels, sewn on – adhesive labels can loosen.
- You may need to provide initial medication and a list of all prescribed medicines which you can obtain from the GP. Check with the Care Home Manager beforehand.
- Establish procedure for emergencies and how and when you should be contacted. Confirm with next of kin who should be contacted in order of preference in case you are not available. Ask what the home's procedure is for contact 'out of hours', weekends or late at night.
- Provide some background information about the person you care for, their personal and family history, likes and dislikes, how they like to be addressed and what makes them feel comfortable. It is helpful to have this typed up so you can provide it by email.
- If the person you care for wears glasses or hearing aids, it is crucial to make sure the home is aware of how they need to be accommodated. It is recommended to include this in your background information and in their Care Plan.
- The resident should have a Care Plan which will be generated by their Social Worker before entering the home. Make sure it is kept updated. You can ask to see it if necessary.
- You are a Care Partner in the care provided by the care or nursing home, Ask for your role as a Care Partner to be agreed and documented.

**Remember, to be able to help others you must first look after yourself, mentally and physically. As a carer, this may sound selfish or not what you are used to doing. However, from other carers experience, we know that it is easy to become overwhelmed without realising. Taking 10 or 20 minutes regularly to do something for you. This will help reenergise you and give you the strength to go on. Be kind to yourself.**

## Tide Carer Cheat Sheet: End of Life, grief and bereavement

- Dementia is a palliative condition. However, the progression of the disease, the length of time someone can live is dependent on each individual. This means there is many unknowns and life can be both routine and unpredictable for a carer.
- Acknowledge, that while caring for someone can be rewarding it can also be a stressful and lonely experience. It is OK to feel overwhelmed but you don't have to do it all yourself. Reach out for help if you need to talk.
- You may experience 'living grief and bereavement'. This is when you feel the emotions of grief and bereavement when the person you care for is still alive. As their dementia progresses the person you knew will 'disappear' in different stages and the relationship you had with them change forever. It's ok to feel this loss, when it comes.
- If possible, speak to the person you care for in the earlier stages of dementia, whilst they still knowingly make decisions. Clarify their wishes around end of life arrangements including whether they want a Do Not Resuscitate (DNR) order in place, what type of burial they would like and how they wish to be remembered.
- Recognise that the person you care for may become frailer, may have problems eating and need more advanced care. Consider what adjustments you may need to make in order to make this an easier experience for you and them.
- If still living at home, consider if the person you care for needs to be in sheltered accommodation, a care home or a hospice. Although it may be a difficult decision to make, remember that this may be the best type of care needed at this time, even if not what you or your loved one originally wanted.
- Realise that you may have a large gap in your life, once the person you care for has passed. Your identity as a carer doesn't stop when you are no longer caring for someone.
- There is no right or wrong way to grieve.
- Speak to your family or friends to talk about how you're feeling. Reach out to your GP or other professionals if you need to talk.
- Try not to feel guilty! It is a natural reaction for many carers but you are doing all you can, under difficult circumstance.

**Remember, to be able to help others you must first look after yourself, mentally and physically. As a carer, this may sound selfish or not what you are used to doing. However, from other carer's experience, we know that it is easy to become overwhelmed without realising. Taking 10 or 20 minutes regularly to do something for you. This will help reenergise you and give you the strength to go on. Be kind to yourself.**

## Glossary

### What all the letters and terms actually mean

**Advanced Care Plan:** a plan you can write at any stage of your life or health which shares your values, goals and preferences regarding future medical care and end of life decisions. This allows your loved ones to act according to your wishes, at a time when they might struggle during a medical emergency.

**Advocacy:** Getting support from another person to help you voice your views and wishes, and to help you stand up for your rights. An advocate helps you feel listened to.

**Alzheimer's disease:** an irreversible and progressive brain disease that slowly destroys memory and thinking ability as well as motor and movement skills. Alzheimer's is a specific disease which is the most common cause of dementia.

**Care Home (or residential care home):** Another name for a residential care home providing personal care and accommodation to those unable to look after themselves.

**Carer:** Someone who is caring for another's health or wellbeing in an unpaid role, either full-time or in a regular capacity. The role may not be formally acknowledged but something that has developed over time. This can be a friend, family member or spouse.

**Carer Coordinator:** the point of contact for carers in each Trust. They can tell you about local support, carer's assessments, carer breaks and respite, different activities and training opportunities and other services provided by Trusts and other organisations.

**Carer's Assessment:** An assessment carried out by Social Services to see if you are entitled to any additional help or benefits. You can refer yourself for an assessment or be referred by your GP, social worker in addition to a number of others.

**Controllership:** If the person you are caring for has been deemed to no longer have mental capacity to make their own decisions and there is no Enduring Power of Attorney in place, someone will have to apply for Controllership to make decisions on their behalf.

**Dementia:** A general term for a decline in mental ability, severe enough to interfere with daily life. Dementia is not a specific disease. However, it is a disease of the brain not a mental health condition.

**Dementia Navigator:** A Dementia Navigator will support any person who has received a new diagnosis of Dementia; someone with an existing diagnosis who may require additional support; and family and carers. The person has to give their consent to be referred to the Dementia Navigator.

**Do Not Resuscitate (DNR)** This is when a senior doctor makes the decision that it may not be in the best interests of the patient to resuscitate them if their heart or breathing stops. This is something you should consider with the person you care for or if not possible, with next of kin if applicable, before they reach the end of life.

**End of Life:** the final stages of life, which may be managed either at home, hospital or in a hospice.

**EPA** – Enduring Power of Attorney

**Holistic:** treatment of the whole person, rather than just the symptoms of a disease, taking into account mental and social factors, to provide a better outcome.

**HSC:** Health & Social Care – An amalgamation of NHS and social services care which are now under the one operating unit in Northern Ireland

**HSCT:** Health & Social Care Trust. The bodies responsible for delivering health and social care services within Northern Ireland. Split into 5 geographical groups to include Belfast, Southern, South Eastern, Northern and Western.

**Living grief:** a sense of loss or grief for someone who is still alive, but no longer able to have the same relationship with you.

**Memory Clinic:** For anyone aged 65 and over who has experienced memory problems for six months or more, where their GP has ruled out other causes. The Memory Clinic carries out assessment and diagnosis. Once the person has received a diagnosis of dementia, they can be referred to the Dementia Navigator. You are referred to the Memory Clinic by your GP, so if you or the person you are caring for is concerned, the first person to speak to is your GP.

**Mental health:** a person's state of mind with regards to their emotional and psychological well-being.

**Mental capacity:** the ability to make the right decisions to look after yourself.

**Nursing home:** A home that provides accommodation, nursing and personal care for those who cannot look after themselves.

**Palliative care:** specialist medical care for those with complex, medical or end of life conditions.

**Primary care:** first point of contact for health care – usually provided by GPs, pharmacists, dentists or opticians.

**Psychiatry of old age:** Specialised treatment and care provided specifically for older adults whose health problems may include dementia, depression, schizophrenia or other conditions.

**Respite care (or carer breaks):** planned or emergency temporary care outside of the patient's home to give their unpaid carer a break.

## The thank yous

To the Health and Social Care Board for giving us the money and support to do this in a way that really worked.

To Edel Quinn who pulled together the initial information, with a very wide brief, whilst in a global pandemic. Ever the professional and, generous with her knowledge.

To Siobhan Gallagher who shared her caring experiences, editing skills and understanding of the system to make this readable; whilst managing her own caring responsibilities, completing post-grad assignments and setting up a business.

## The disclaimer:

We acknowledge that some of the information in this handbook may already be out of date. Please let us know if you spot anything that is inaccurate so we can correct it for the next time. We aim to update the handbook regularly.

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