# The Care Compass

Navigating Later-Life Care Together

# A Quiet Place to Start

*Free, practical guidance for whatever's ahead — one stage at a time.*

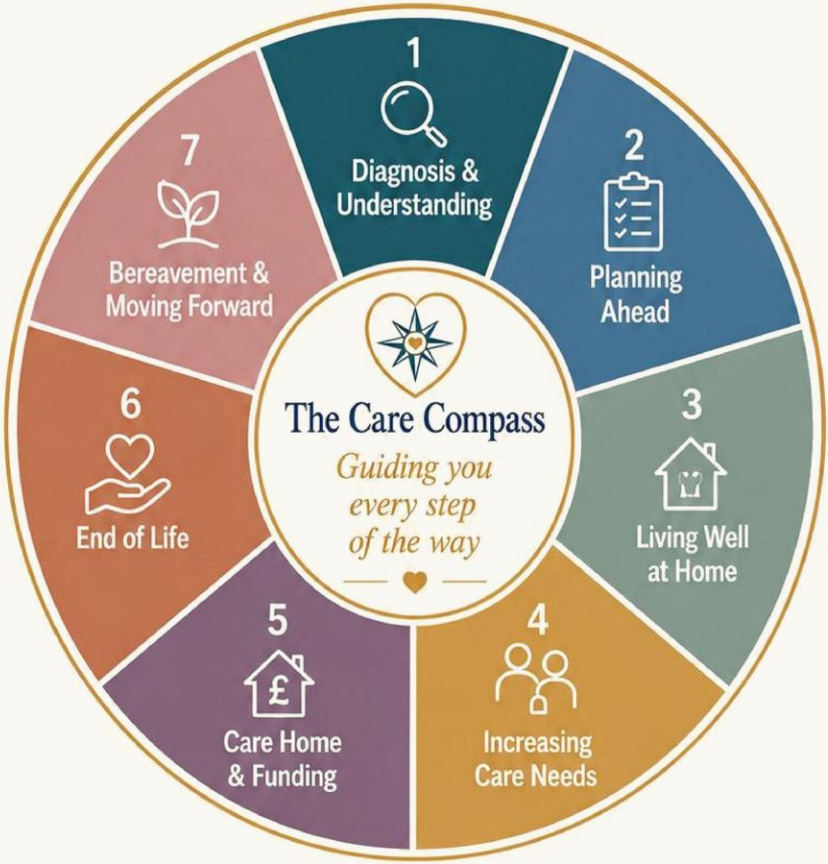
From: _____ To: _____



www.thecarecompass.uk

# How to Use This Booklet

This isn't meant to be read cover to cover.
Find whichever stage feels closest to where you are right now, and start there.
Come back to the others whenever you need them.






*Wherever you are, you don't have to navigate it alone.*

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The Care Compass

**STAGE 1 · Diagnosis & Understanding**

1

## Spotting the signs

Repeating questions, getting lost somewhere familiar, or a real change in personality can all be early signs. It's rarely just one thing.

2

## Getting a diagnosis

It usually starts with a GP, who may refer to a memory clinic for tests. There's no need to work it all out yourself first.

3

## Right after diagnosis

You don't have to decide everything at once. One step at a time is genuinely enough for now.

4

## However you feel is normal

Relief, grief, denial, numbness — there's no right way to feel, and it can change day to day.

A diagnosis is a starting point, not a verdict.
Most people live well for years afterwards,
with the right support around them.

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**STAGE 1 ·**
Diagnosis & Understanding

## QUICK RECAP

**Spotting the signs:** early changes can be easy to miss.

**Getting a diagnosis:** it usually starts with a GP.

**Right after diagnosis:** one step at a time is enough.

**However you feel is normal:** all emotions are valid.

## CONTACTS & RESOURCES

| | |
|---|---|
| Alzheimer's Society Dementia Support Line | 0333 150 3456 |
| Admiral Nurses | 0800 888 6678 |
| Your GP surgery: | _____ |
| Memory clinic/local dementia service: | _____ |

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**STAGE 2** • Planning Ahead

1

## Set up a Lasting Power of Attorney

Lets someone you trust make decisions if you're ever unable to. Once capacity is lost, this can't be set up at all, only applied for through the courts, slower and harder.

2

## Rules differ across the UK

Scotland uses a different system to England and Wales, with its own registration process. Check which applies to you before starting.

3

## Understand what care might cost

Funding rules and thresholds vary by nation. Our free Care Cost Calculator gets the right figures for wherever you are.

4

## Start the conversation early

Talking about wishes and finances before a crisis makes every decision afterwards easier, for everyone.

Planning ahead isn't about expecting the worst. It's about making sure decisions, whenever they're needed, are easier for everyone.

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**STAGE 2** • Planning Ahead

## QUICK RECAP

**Set up a Lasting Power of Attorney:** appoint someone you trust while you still have the mental capacity to do so.

**Rules differ across the UK:** Scotland and NI each have their own systems — check which applies to you.

**Understand what care might cost:** funding rules and thresholds vary by nation — use our free calculator.

**Start the conversation early:** talking about wishes and finances now makes decisions easier for everyone.

## CONTACTS & RESOURCES

| | |
|---|---|
| Office of the Public Guardian | 0300 456 0300 |
| Citizens Advice | 0800 144 8848 |
| Your solicitor: | _____ |
| **thecarecompass.uk/care-costs.html** for the free Care Cost Calculator | |

# The Care Compass

**STAGE 3**
Living Well at Home

1

## Infections (especially UTIs)

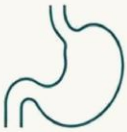
A UTI can cause sudden confusion, hallucinations and falls. It isn't always the dementia getting worse.

2

## Dehydration

Not drinking enough can bring on confusion fast, especially in hot weather or if fluids are being missed.

3



## Constipation

An overlooked but common cause of sudden agitation and confusion.

4

## Certain medications

Some sedatives, painkillers and antihistamines can trigger sudden confusion as a side effect.

5

## Untreated pain

Pain that can't be put into words often shows up as agitation or distress instead.

6

## Noise and overstimulation

Sudden or loud noise, or a chaotic environment, can overwhelm and cause real distress.

Each of these is usually treatable. If a change is sudden, it's always worth asking a GP before assuming it's the dementia progressing.

## QUICK RECAP

Infections (especially UTIs) can cause sudden confusion, hallucinations and falls.

Dehydration can bring on confusion fast, especially in hot weather or if fluids are being missed.

Constipation is an overlooked but common cause of sudden agitation and confusion.

Certain medications can trigger sudden confusion as a side effect.

Untreated pain often shows up as agitation or distress instead.

Noise and overstimulation can overwhelm and cause real distress.

## CONTACTS & RESOURCES

| | |
|---|---|
| NHS 111 | Dial 111 |
| Admiral Nurses | 0800 888 6678 |
| Carers UK | 0808 808 7777 |
| Your GP surgery: | _____ |
| Local council adult social care: | _____ |

The Care Compass

STAGE 4 • Increasing Care Needs

1

## Recognising when more help is needed

Needing more support isn't a failure, yours or theirs. It's a normal part of the journey, and getting help early makes it easier for everyone.

2

## Managing changes in behaviour

Agitation or aggression is often distress, pain, or confusion being expressed the only way it can. Staying calm and not taking it personally genuinely helps.

3

## Bringing in paid support

Extra help at home, even a few hours a week, can take real pressure off, and isn't an admission that you can't cope.

4

## Balancing work and caring

Employers must consider flexible working requests, and Carer's Leave gives unpaid time off. You don't have to manage this entirely alone.

Needing more help is a sign of a situation changing,
not a sign of failure.
Asking for support is one of the most caring things you can do.

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STAGE 4 • Increasing Care Needs

## QUICK RECAP

**Recognising when more help is needed:** it's normal to need more support as things change.

**Managing changes in behaviour:** understanding the reasons behind behaviour can help you respond with compassion.

**Bringing in paid support:** extra help at home eases pressure and supports everyone involved.

**Balancing work and caring:** workplace rights and support can help you manage both.

## CONTACTS & RESOURCES

| | |
|---|---|
| Carers UK | 0808 808 7777 |
| Admiral Nurses | 0800 888 6678 |
| Your local homecare agency: | _____ |
| Your employer's HR/flexible working contact: | _____ |

# The Care Compass

**STAGE 5** • Care Home & Funding

1

## Understanding who pays

Funding depends on savings, income, and which UK nation you're in. Rules genuinely differ, our free Care Cost Calculator gets the right figures for you.

2

## Choosing a care home

Visit more than once, at different times of day. Trust your gut about atmosphere as much as the paperwork.

3

## Settling in takes time

The first few weeks are often the hardest, for everyone. It usually does get easier, even when it doesn't feel like it will.

4

## Don't miss NHS Continuing Healthcare

If health needs are significant, some or all care costs may be fully funded by the NHS, regardless of savings. It's often missed and worth asking about directly.

This is one of the hardest decisions in the whole journey. Take the time you need, and don't be afraid to ask questions more than once.

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STAGE 5 • Care Home & Funding

## QUICK RECAP

**Understanding who pays:** funding depends on savings, income, and which UK nation you're in.

**Choosing a care home:** visit more than once and trust your gut about atmosphere as much as the paperwork.

**Settling in takes time:** the first few weeks are often the hardest, but it usually does get easier.

**Don't miss NHS Continuing Healthcare:** if eligible, some or all care costs may be fully funded by the NHS.

## CONTACTS & RESOURCES

| | |
|---|---|
| Age UK Advice Line | 0800 678 1602 |
| Care Quality Commission — check ratings at **cqc.org.uk** | 03000 616161 |
| Your local council adult social care: | _____ |
| Chosen care home: | _____ |

# The Care Compass

## STAGE 6 • End of Life

1

### Recognising the final days

Changes in breathing, sleeping more, or less interest in food and drink can be signs the body is naturally slowing down. It doesn't mean today or tomorrow, but it's worth knowing.

2

### Palliative and hospice care

This is about comfort and quality of life, not giving up. Hospice teams and palliative nurses can support the whole family, not just the person who is unwell.

3

### If death happens at home

If it's expected, call the GP or NHS 111, not 999. There's no need to rush. Take the time you need before making any calls.

4

### Being present, in whatever way feels right

There's no right way to say goodbye. Presence, quiet, words, or simply sitting nearby can all be enough.

This is one of the hardest parts of the whole journey.
Be gentle with yourself. There is no right way to do this.

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STAGE 6 • End of Life

## QUICK RECAP

**Recognising the final days:** changes can be signs the body is naturally slowing down.

**Palliative and hospice care:** about comfort, dignity, and support for the whole family.

**If death happens at home:** call the GP or NHS 111, not 999. There's no need to rush.

**Being present, in whatever way feels right:** there's no right or wrong way to say goodbye.

## CONTACTS & RESOURCES

| | |
|---|---|
| Marie Curie Support Line | 0800 090 2309 |
| NHS 111 | Dial 111 |
| Your GP surgery: | _____ |
| Hospice or palliative team (if involved): | _____ |

The Care Compass

STAGE 7 • Bereavement & Moving Forward

1

## Registering the death

Must be done within 5 days in England, Wales and Northern Ireland (8 days in Scotland). You'll need the death certificate for almost everything that follows.

2

## Probate and practical affairs

Sorting the estate, accounts, and property takes time. There's no need to rush, most things can wait a few weeks while you take stock.

3

## Grief has no timeline

However you're feeling, whenever you're feeling it, is valid. There's no 'getting over it,' only learning to carry it differently.

4

## Moving forward isn't forgetting

Finding moments of joy again isn't a betrayal. It isn't linear, and it's genuinely okay to feel ready before you think you should be.

Grief doesn't follow a straight line, and neither does moving forward.
Be patient with yourself. This takes as long as it takes.

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STAGE 7 • Bereavement & Moving Forward

## QUICK RECAP

**Registering the death:** must be done within 5 days and you'll need the death certificate for almost everything that follows.

**Probate and practical affairs:** sorting the estate, accounts, and property takes time. There's no need to rush.

**Grief has no timeline:** however you're feeling, whenever you're feeling it, is valid.

**Moving forward isn't forgetting:** finding moments of joy again isn't a betrayal. It isn't linear.

## CONTACTS & RESOURCES

| | |
|---|---|
| Cruse Bereavement Support | 0808 808 1677 |
| Probate helpline | 0300 303 0648 |
| Solicitor handling the estate (if any): | _____ |
| Someone I can call, day or night: | _____ |
| Tell Us Once — reports the death to most government departments (DWP, HMRC, passport office, DVLA) in one go | gov.uk/tell-us-once |

# Need Help? Start Here.

If you need help right now, here's exactly who to call.

**Life-threatening emergency**
Call 999

**Urgent but not life-threatening**
Call 111 (NHS)

**Struggling to cope, or worried about someone**
Samaritans: 116 123 (free, 24/7)

**Dementia-specific advice, any time**
Admiral Nurses: 0800 888 6678

**Carer support and guidance**
Carers UK: 0808 808 7777

*You don't have to navigate it alone.*

www.thecarecompass.uk

# Thank you for letting this be part of your journey, however small a part.

*You don't have to navigate it alone.*

Scan to explore

www.thecarecompass.uk

If this helped, the kindest thing you can do is pass it on.

Print another free copy at thecarecompass.uk, or hand this one on.

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EVERY STAGE · Useful Any Time

# Who's Who in Your Care Team

Different professionals do different jobs. Here's who does what.

### Social Worker / Care Coordinator

Arranges a care needs assessment and coordinates support. Usually your first point of contact with the council.

### GP

Your central point for physical health. Refers on to specialists, memory clinics and district nursing as needed.

### District Nurse

Visits at home for medical and nursing needs — wound care, medication, catheters and similar.

### Occupational Therapist (OT)

Assesses the home for safety and equipment — rails, ramps, adapted seating — to help someone stay independent.

You don't need to remember every name at once. Ask anyone in your care team who they are and what they do.

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EVERY STAGE · Useful Any Time

# Who's Who, Continued

A few more roles you might come across along the way.

### Admiral Nurse

A specialist dementia nurse, for families where dementia is part of the picture. Not available everywhere — ask if there's one locally.

### Home Carer / Care Worker

Provides day-to-day personal care at home — washing, dressing, meals, medication prompts — on a scheduled visit basis.

### Memory Clinic Team

Carries out assessment, diagnosis and ongoing specialist review, usually a mix of psychiatrists, psychologists and specialist nurses.

### Care Home Manager

Once in a care home, your main point of contact for day-to-day questions about care, wellbeing and any concerns.

Keep this page and come back to it whenever a new name or job title comes up.