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Living with Dementia – A Carer's Perspective

Zoe Harris

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My husband Geoff experienced poor care because he was unable to express his needs.



2004



I kept a diary so I knew I was already looking up symptoms of dementia in 2004.

2005



Our GP suggested Geoff's memory problems were the temporary result of a cold.

2006

The older person's psychiatrist treated Geoff like a vegetable.



2007



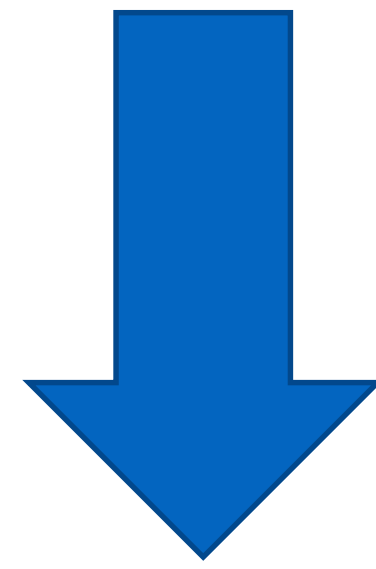
Increasingly confused, Geoff was losing one skill after another.

2008



Finally, a diagnosis. It meant he could go on Aricept and tell his friends and family.

2009: Diagnosis



Aricept - Certainty - Clarity - Anxiety

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Geoff was able to learn the new gate code, but then lost it when they stayed open for maintenance for a few days.

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The bus driver could have shown more compassion when Geoff muddled up his bus pass with the other cards in his wallet.



A GPS Tracker may have helped find Geoff when he 'wandered' but they would still have been extremely traumatic events.



Geoff's problem with the TV remote control was not just about getting confused with too many buttons, he wanted to press 6 to get the 6 o'clock news.

“Dementia is not about
losing the car keys...
it’s about not knowing what
to do with them when you
find them.”

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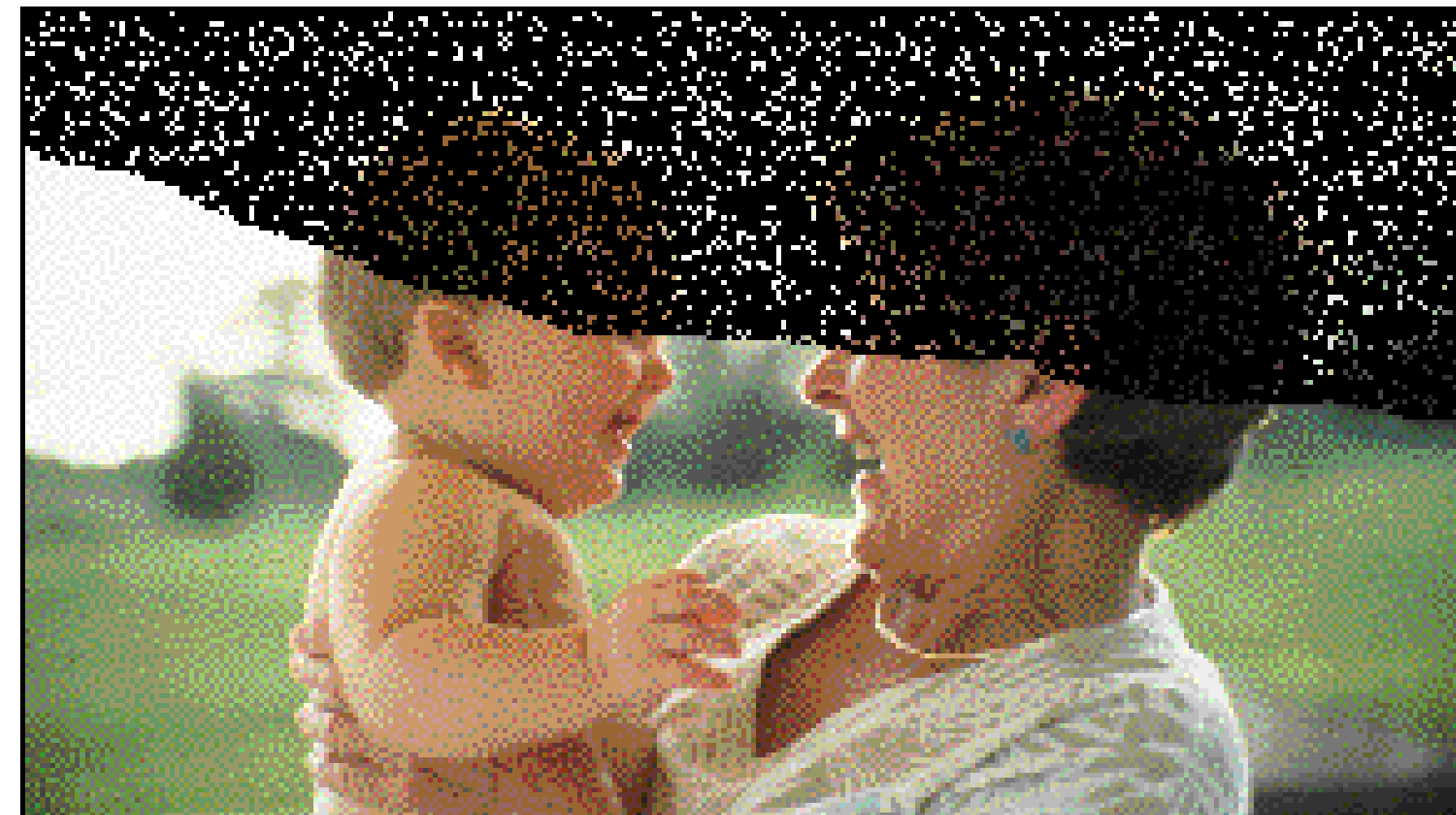
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This is what Geoff is likely to have seen with a detached retina.



Diary extracts:

I'm going to have to find a lot more patience from somewhere...

Even the most innocuous subjects can cause anxiety...

I'm not getting the balance right, between telling him what's going on and not overloading him with detail....

He clung to me for a hug and said 'This is awful'.

I'm beginning to lose the plot...



Going into an assessment ward meant he could come off all the antipsychotics that appeared to be doing more harm than good.

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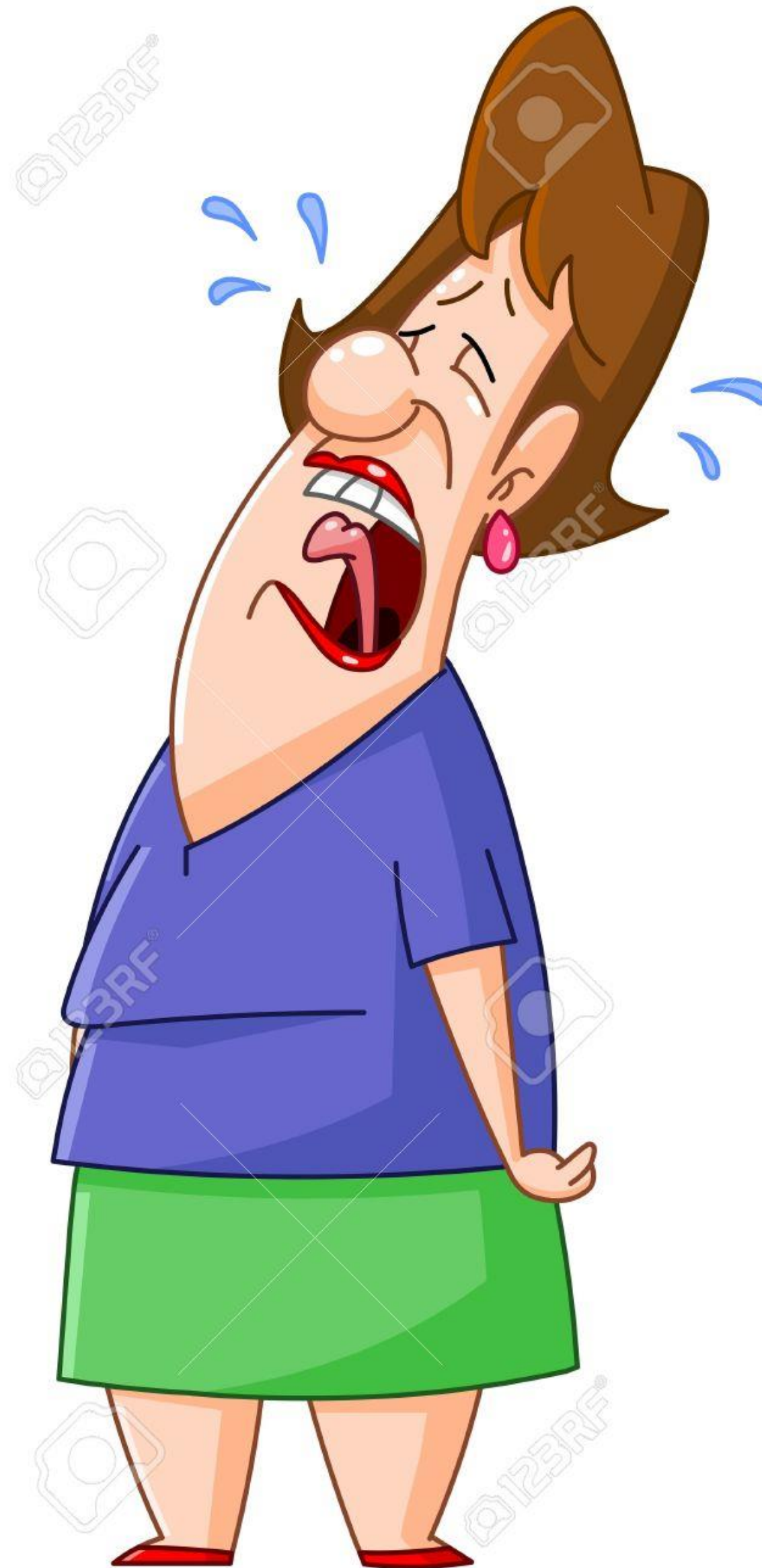
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Geoff drank his tea black, but he'd often be offered a cup of milky tea by well meaning but uninformed staff.



He had developed a tendency to tip his chair over, so it was important that the chair was pushed up against the wall.



It took weeks to identify that this lady was suffering from toothache.

RAPID RELIEF
FROM SENSITIVE TEETH



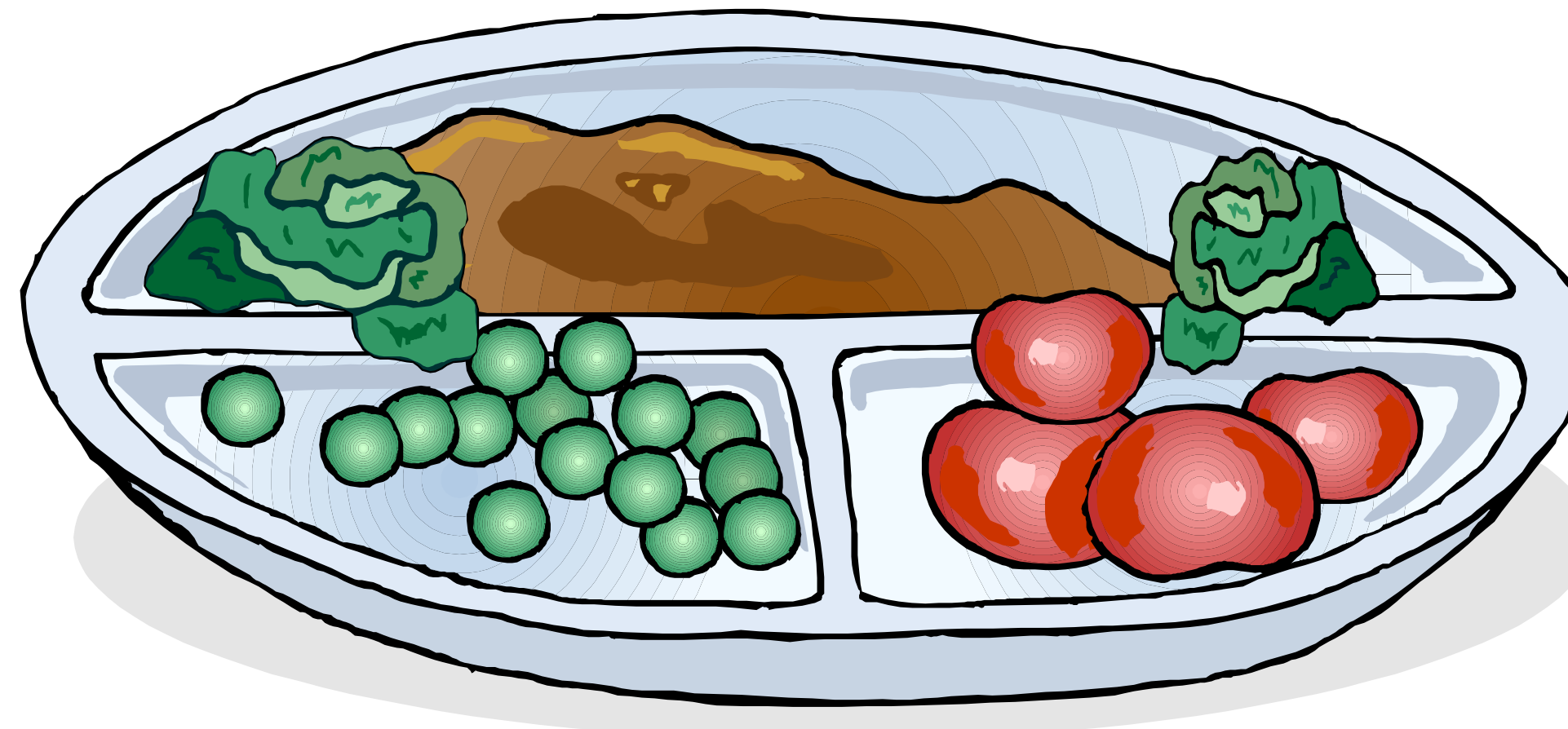
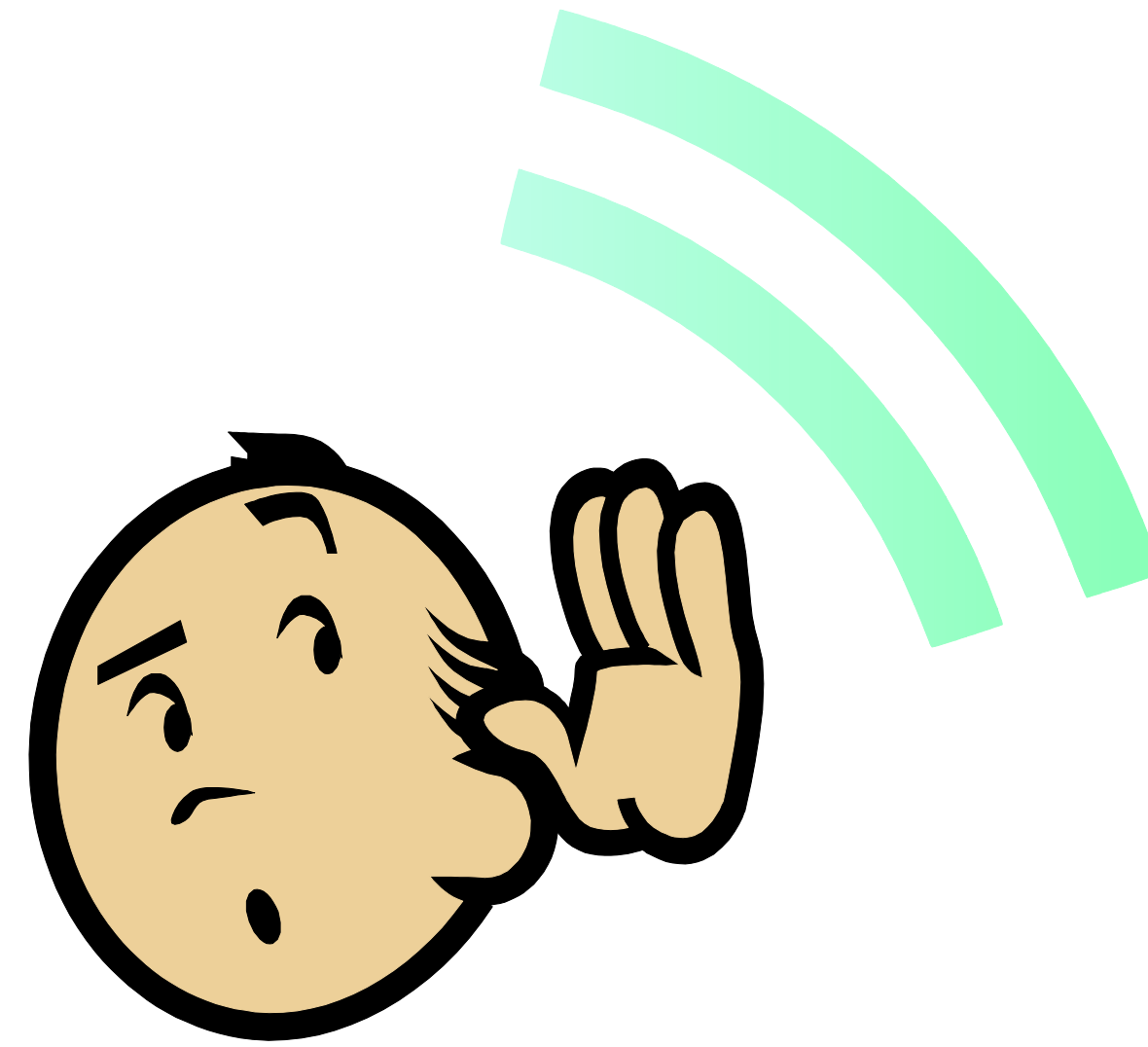
Clinically proven relief.
Works in 60 seconds.*

*When used as directed on pack. Brush thoroughly twice a day or as directed by dentist. Sensodyne is a registered trademark of GlaxoSmithKline Group of Companies.



Please keep
Geoff's chair
pushed up against
the wall so he
can't tip it over.

I started sticking notes on his
bedroom wall...



Remember-I'm-Me Standard Care Chart...

The image shows a 'Remember-I'm-Me Standard Care Chart' form. On the left is a large light blue box labeled 'More information or today's note...'. Below it is a 'Key Carer' field. The main chart area contains two columns of icons with corresponding text boxes. The first column includes icons for important people, dates, activities, TV/radio, pets, religious preferences, tea/coffee, and favourite meals. The second column includes icons for hearing, glasses, toilet, bath, bedding, teeth/dentures, allergies, and mobility aids. A hand holding a 'Care Charts UK' marker is pointing at the 'teeth/dentures' icon. At the bottom, there is a footer with the website 'www.carechartsuk.co.uk', contact information, and a copyright notice for Performance Publications Limited 2012.

More information or today's note...

My name is _____

I like to be called _____

Photo

The important people in my life.

What my hearing is like.

Dates that are important to me.

What you need to know about my eyesight and glasses.

The activities that I am interested in.

The level of assistance I need for my personal care.

My favourite TV and/or radio programmes.

My preferences and usual bathing routine.

My favourite pets, and other thoughts on animals.

What bedding / pillows I prefer and my normal routine.

My religious preferences.

What I'd like you to know about my teeth or dentures.

How I take my tea or coffee and drinks I like or dislike.

Allergies and phobias I suffer from.

My favourite meal(s) and food I dislike or can't eat.

What aids I need for my mobility.

"Remember I'm Me" Care Chart Ref: RIMWC-01

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Another visual communications product from Care Charts UK.

Care home relationships...



Carers



Management



Other staff



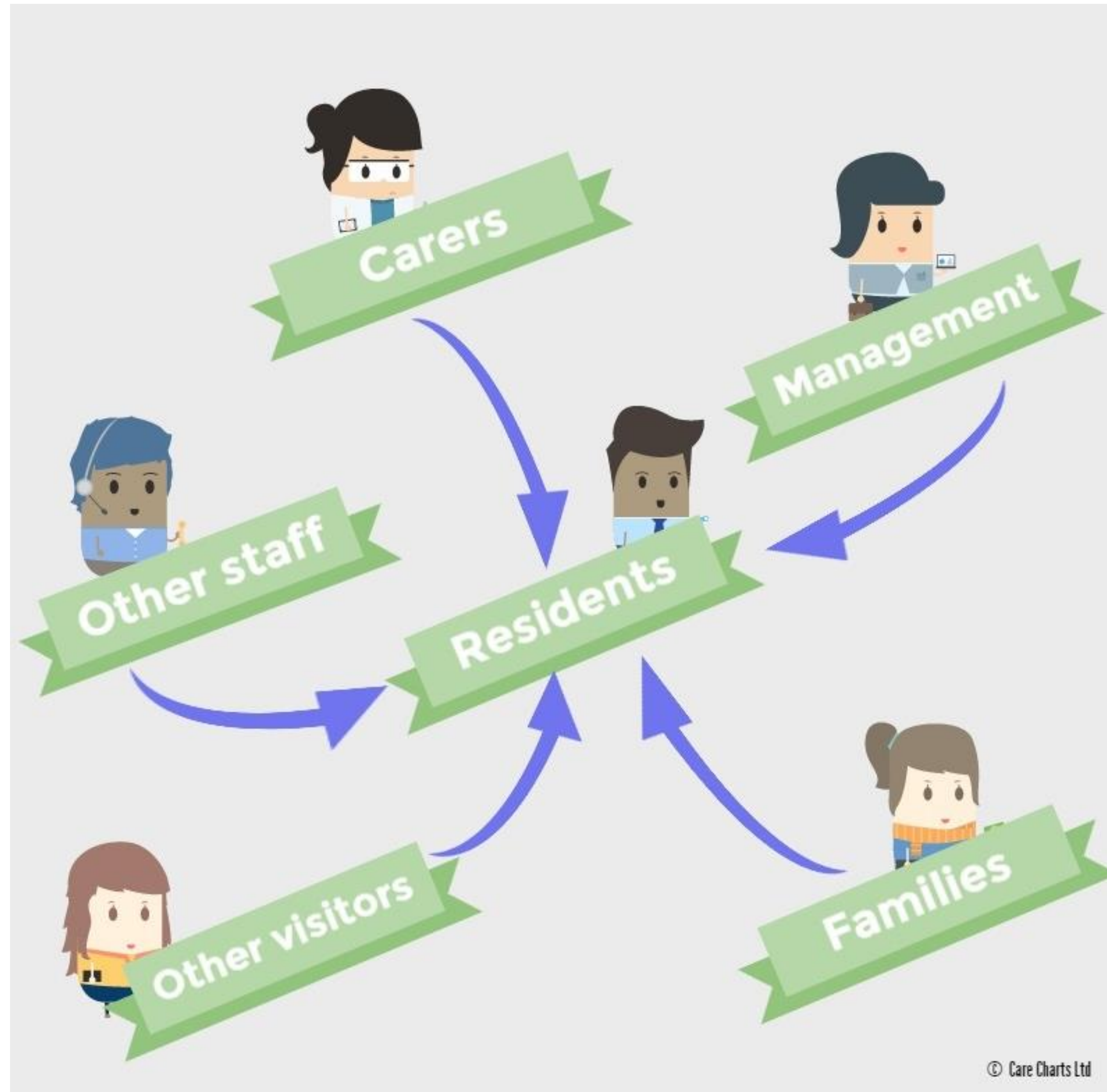
Families

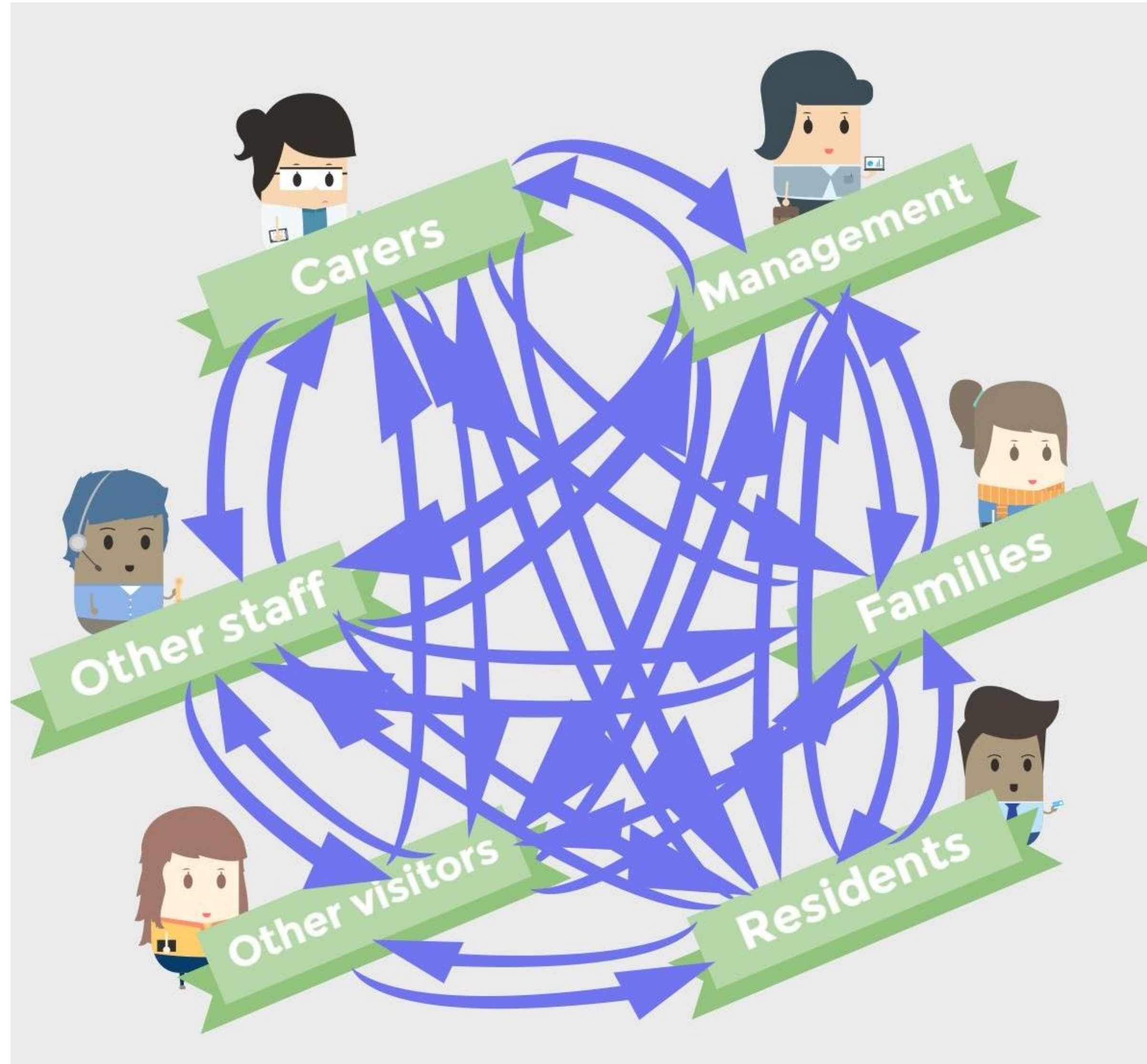


Other visitors



Residents





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Put yourself in their position

Try sitting in an individual's chair for a few minutes and look at the world as they see it. Seeing things from their point of view might help explain unusual behaviour.



A resident's room is their home

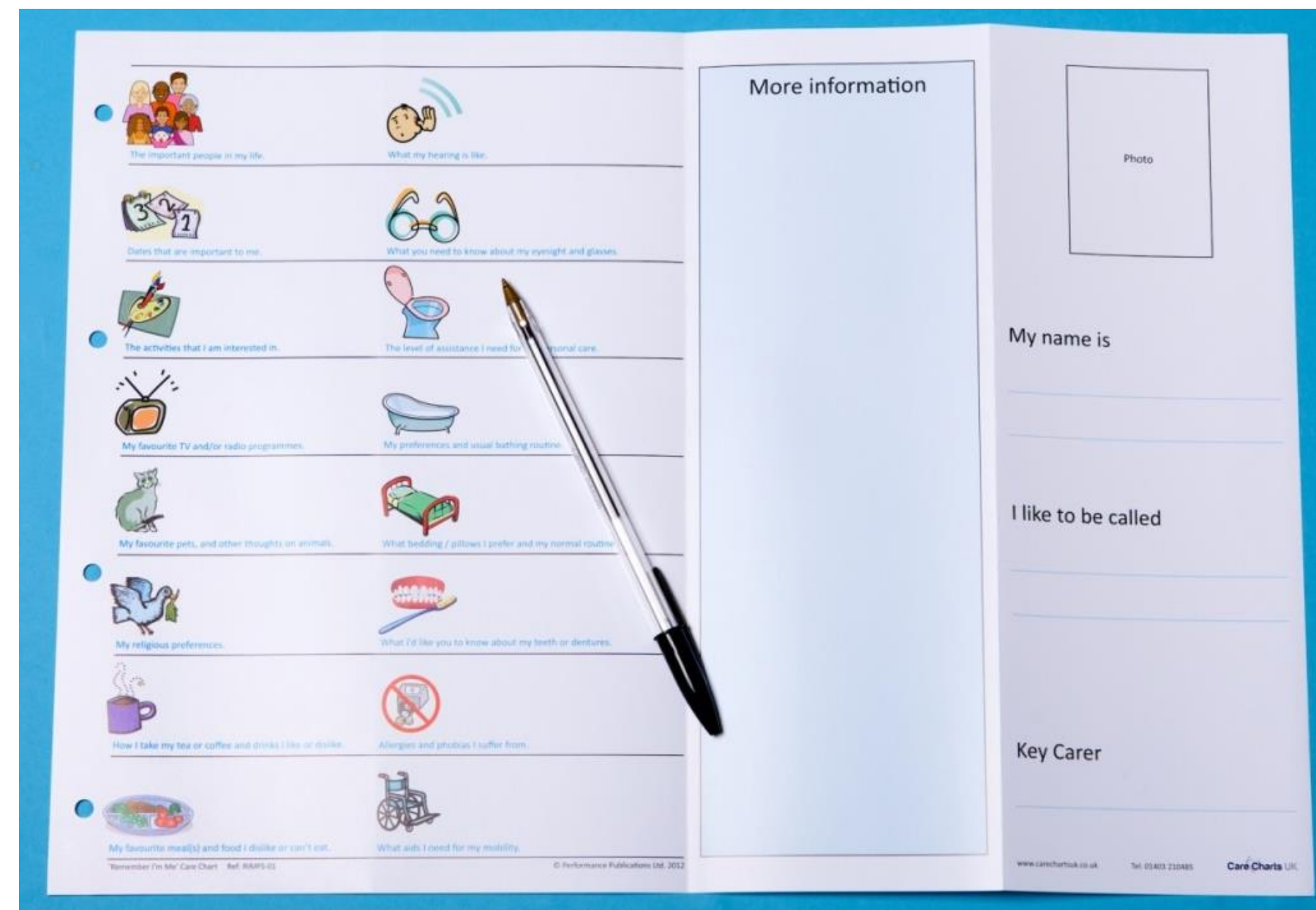
Remember that when you are going into an individual's room you are probably going into the only space they can still call their own. Act as you would in anyone's home, giving the person your full attention.



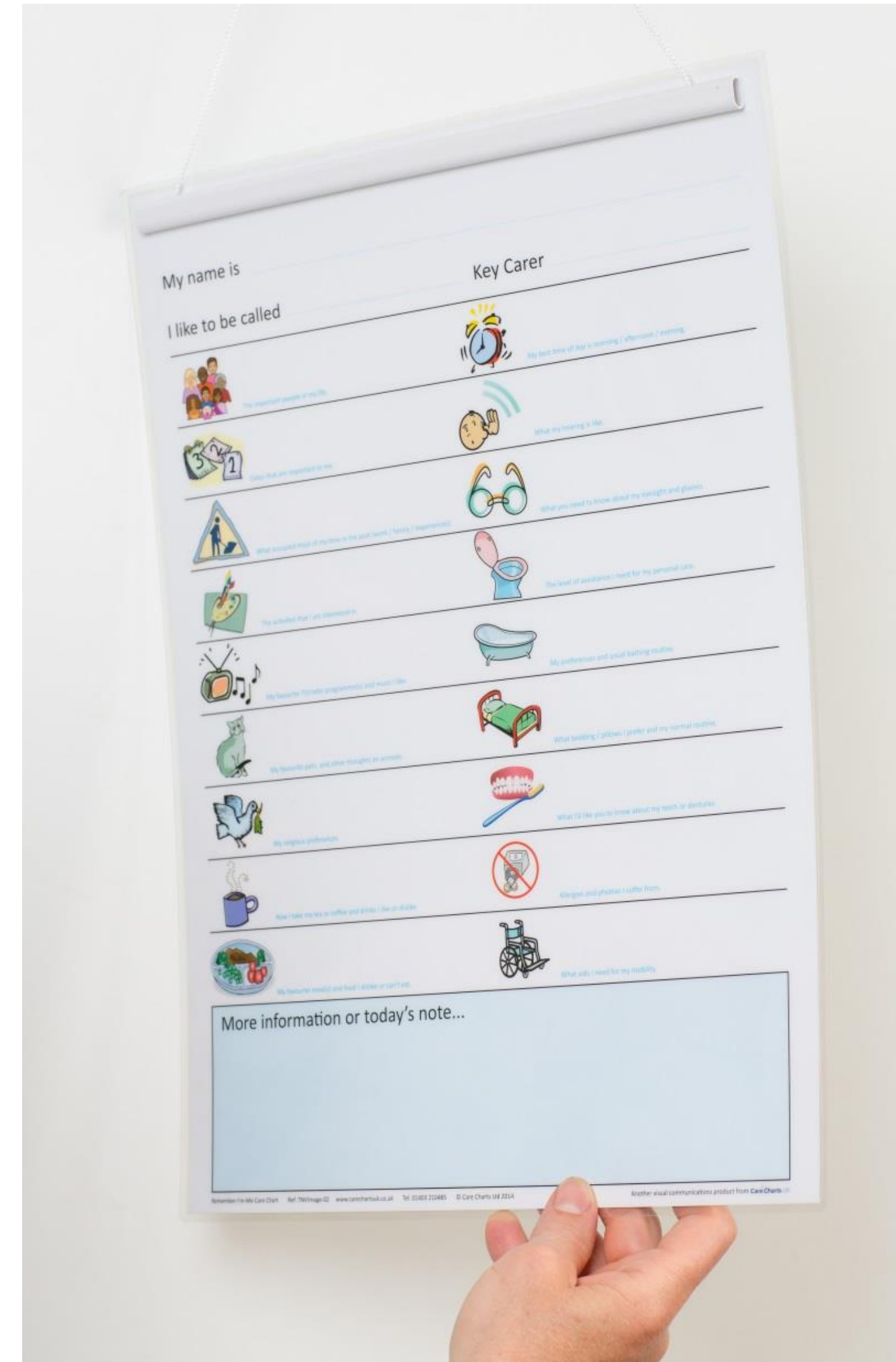
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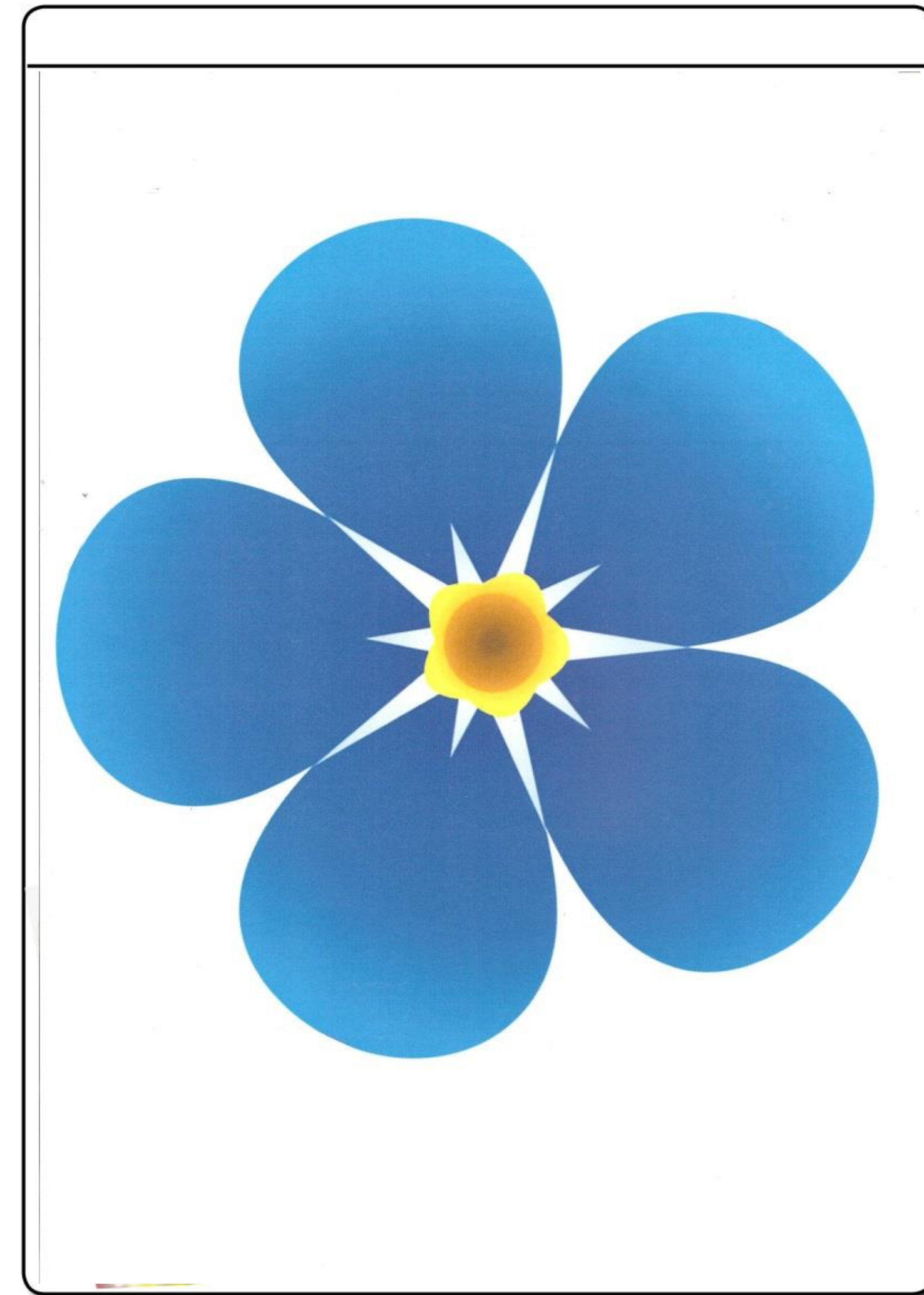
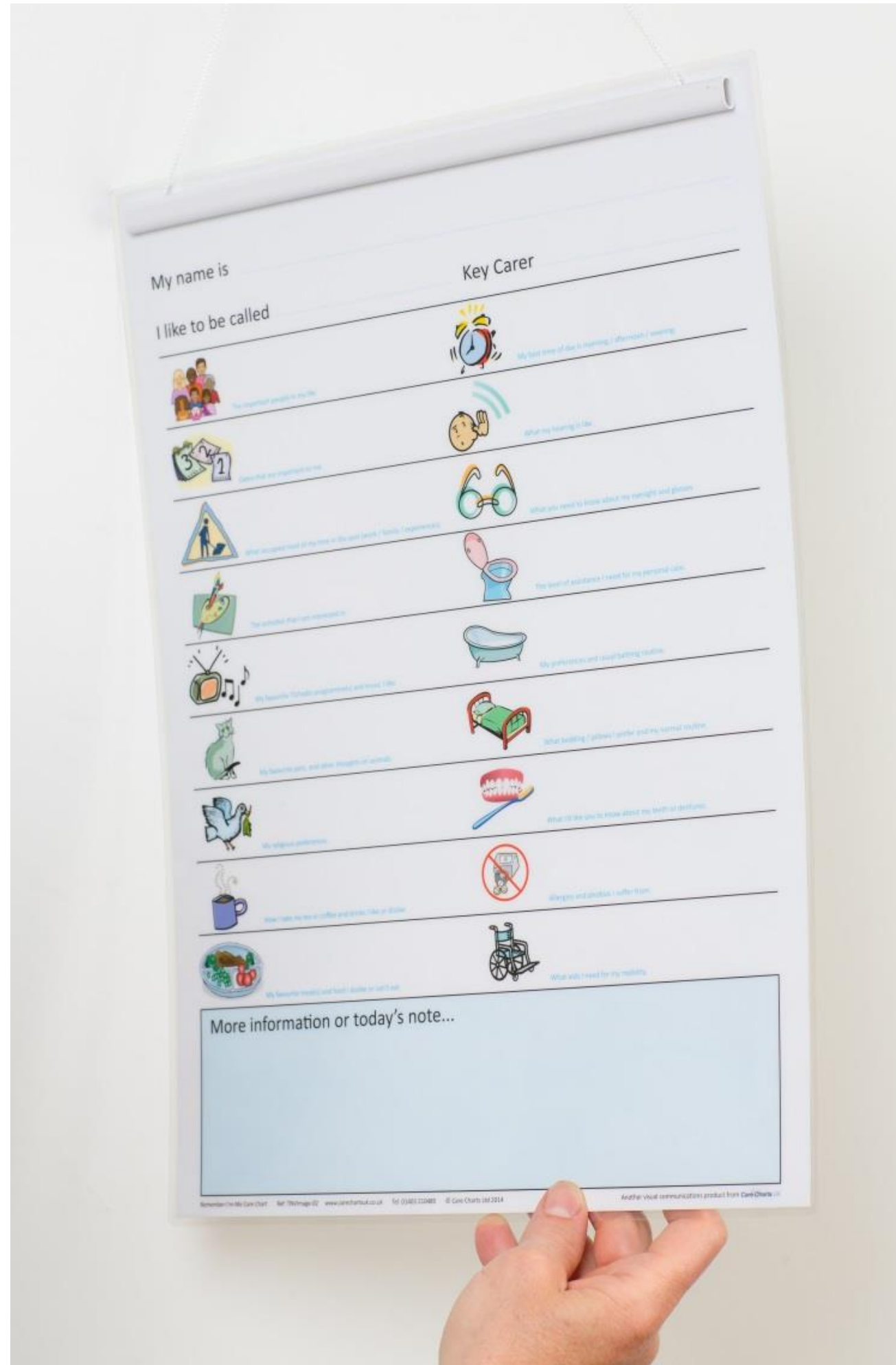
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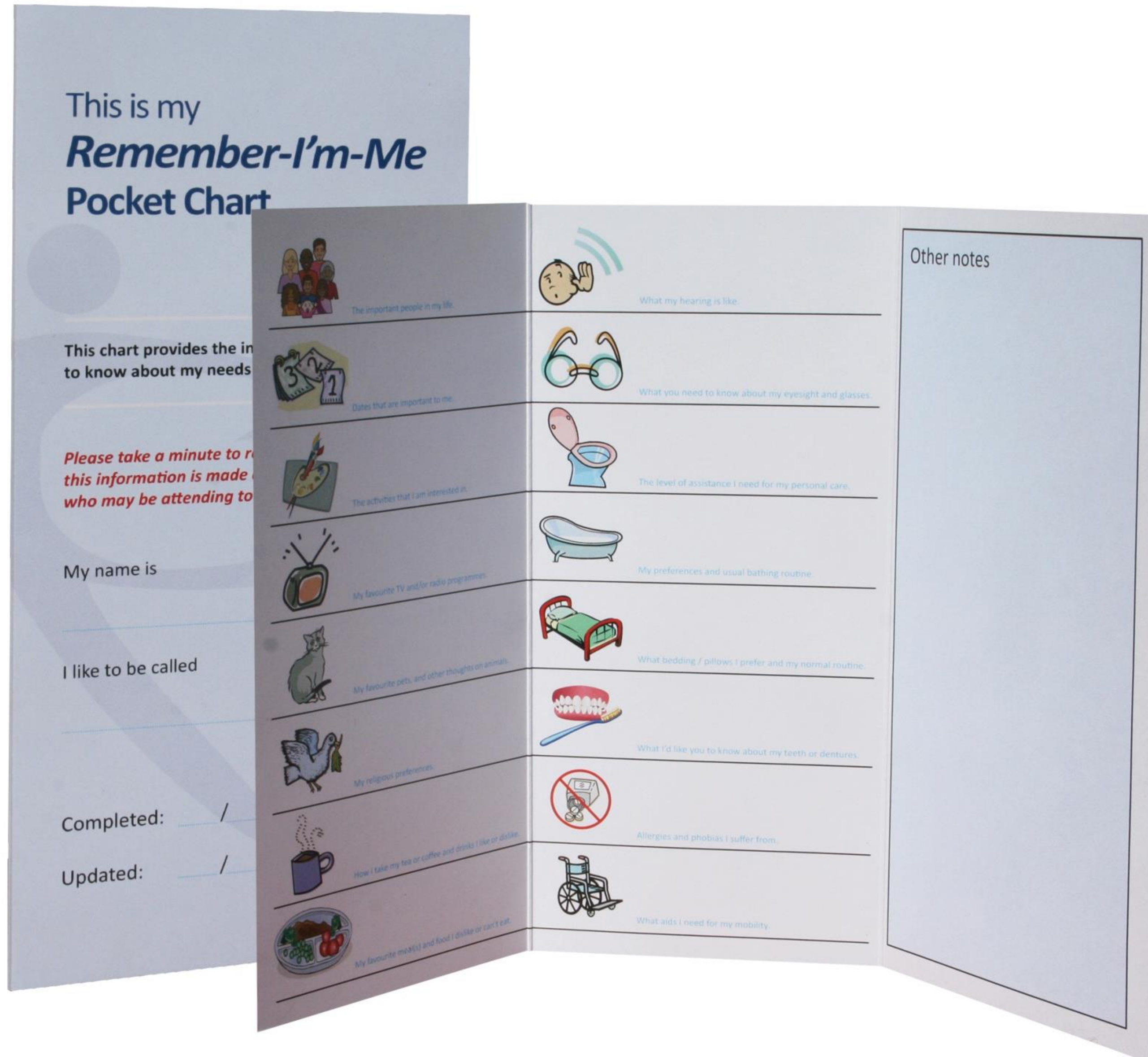


Twist-N-View Image...



Twist-N-View Display...



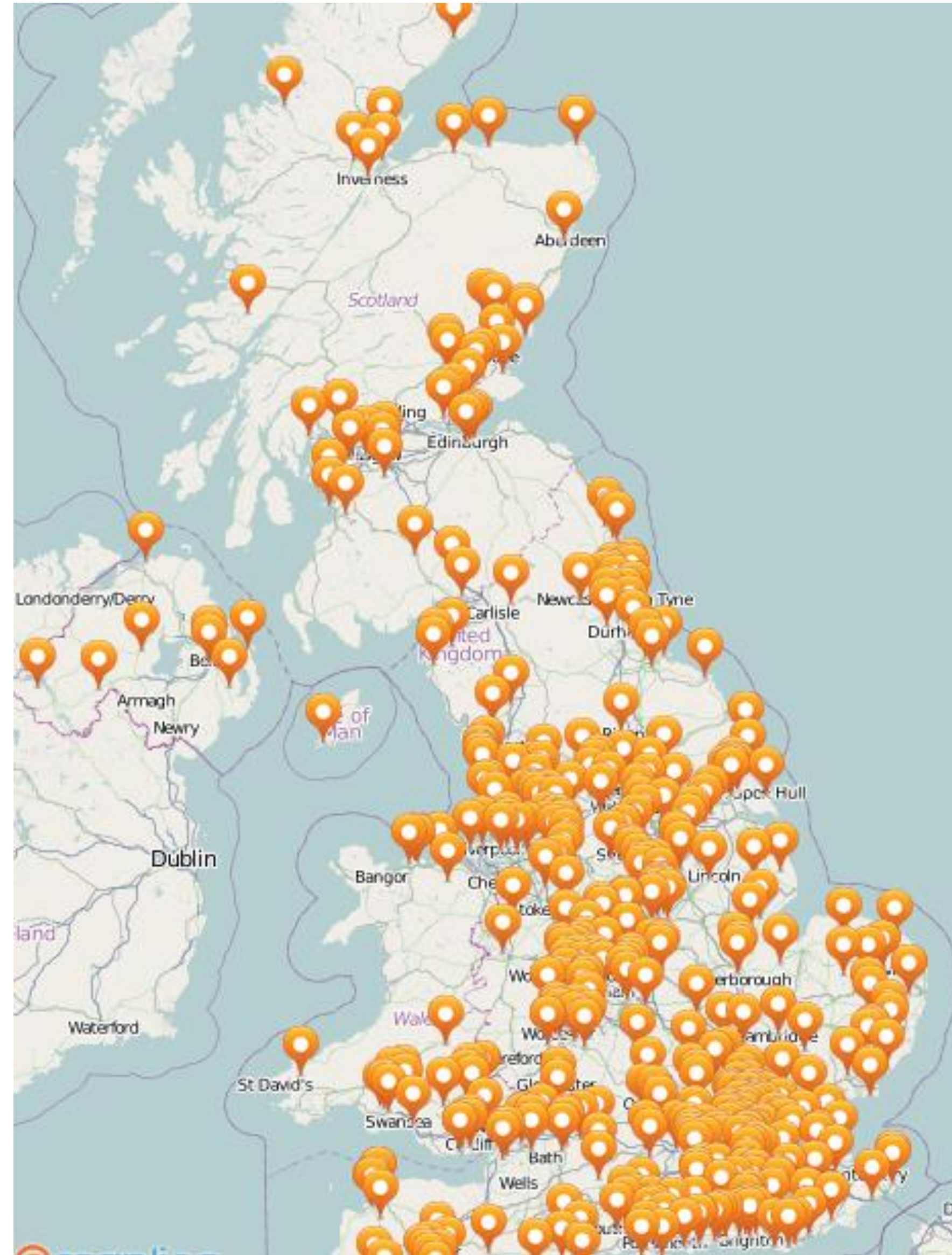


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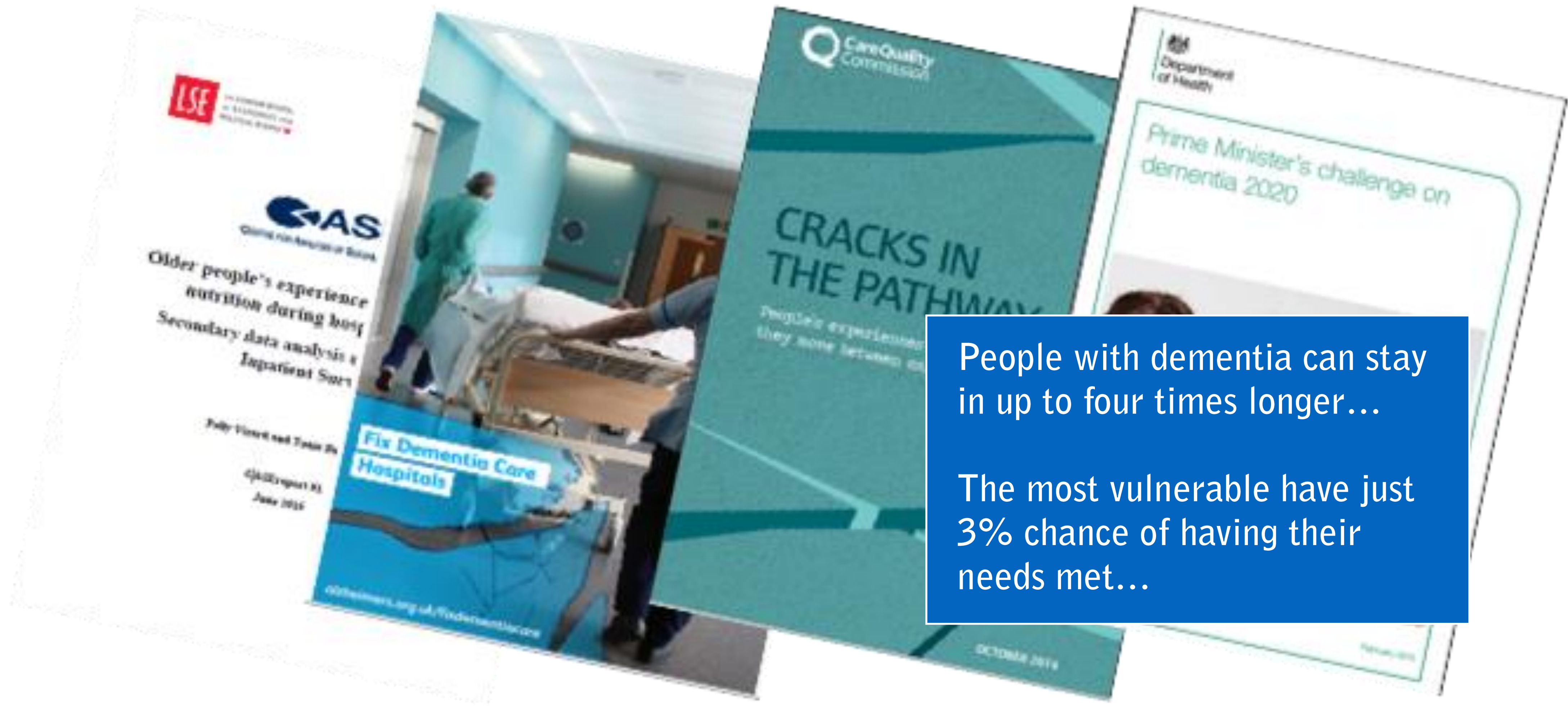
Remember-I'm-Me Care Charts have been adopted by over 1,000 care homes and home care agencies throughout the UK.

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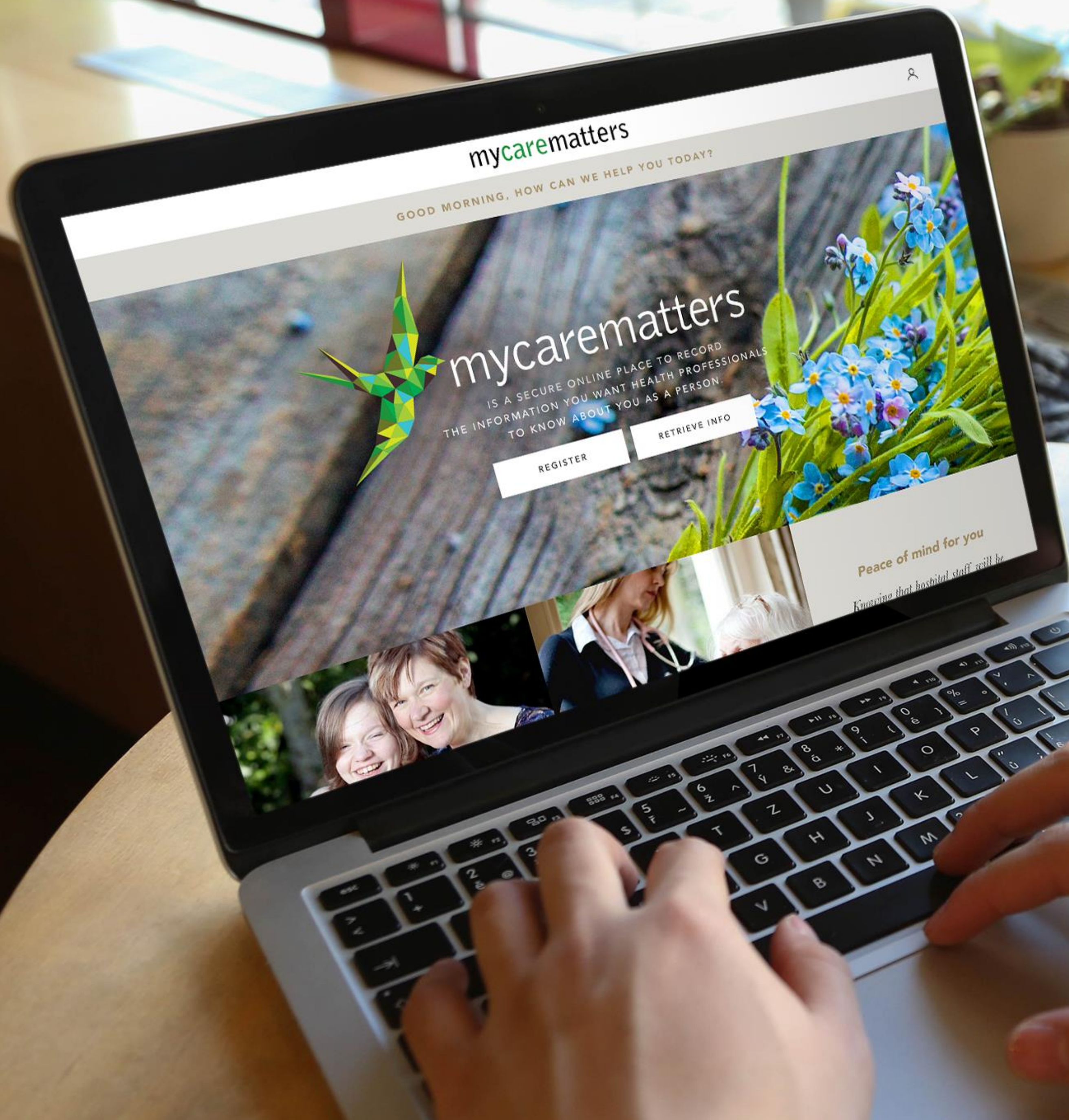
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People with dementia can stay in up to four times longer...
The most vulnerable have just 3% chance of having their needs met...

- 25% of UK hospital beds are occupied by people with dementia
- Average patient age is 80
- Numbers of people over 85 set to double within 20 years





mycarematters
GOOD MORNING, HOW CAN WE HELP YOU TODAY?



mycarematters
IS A SECURE ONLINE PLACE TO RECORD
THE INFORMATION YOU WANT HEALTH PROFESSIONALS
TO KNOW ABOUT YOU AS A PERSON.

REGISTER RETRIEVE INFO



Peace of mind for you
Knowing that hospital staff will be

Mycare matters is an online platform where people can upload the information they want healthcare professionals to know about them.

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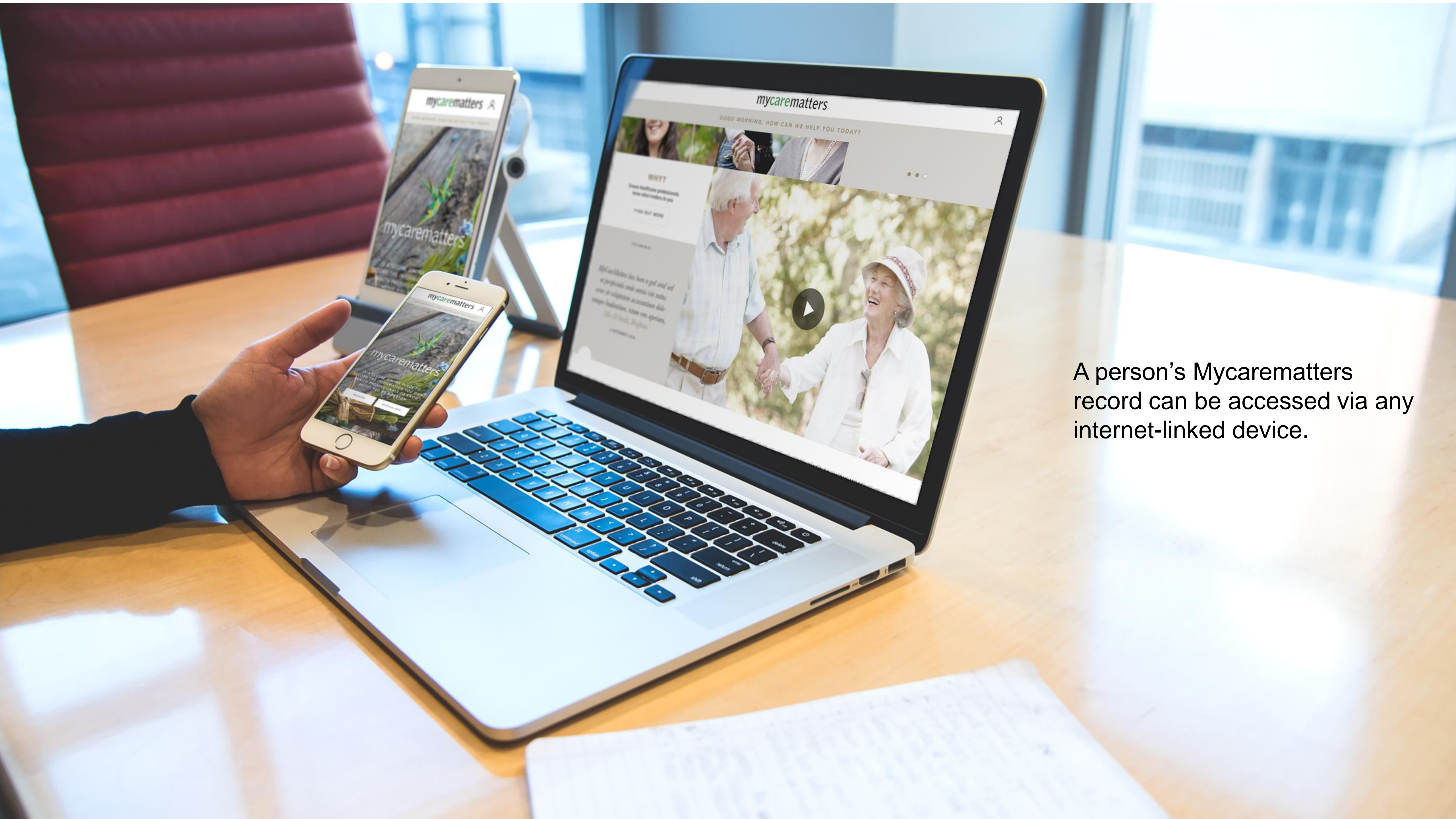
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Hospital staff just need to tap in your MCM unique code to view or download and printout your Mycaremmatters record.



A person's Mycarematters record can be accessed via any internet-linked device.

Meet Reg and Betty

Reg is often admitted to hospital with urinary tract infections. He is one of the first people we have signed up for the current trial.



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zoe@mycaresmatters.org

 **Care Charts** UK

www.carechartsuk.co.uk

Tel: 01403 210485

enquiries@carechartsuk.co.uk

Because-I-Care Training

training@because-i-care.co.uk