



CARING FOR VULNERABLE LOVED ONES

The People's Health Alliance

'Caring for Vulnerable Loved Ones' by the The People's Health Alliance.

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Table Of Contents

About The People's Alliance	01
About this Resource	02
Navigating the UK care provision	03
Choosing the Right Care	03
Considering Care Options	04
Care at home	05
Residential Care & Nursing Homes	07
Warning Signs To Look Out For	09
Care Comparison	11
Case Studies	12
Acronyms	22
Dementia Resources	24
Next Steps	28



About The People's Alliance

The People's Health Alliance (PHA) is a division of The People's Alliance CIC, an integrated health initiative that educates, supports and empowers people to take responsibility for their own health and health solutions. PHA is an organic, people lead, apolitical organisation; not interested or involved in politics.

EDUCATE

We provide independently created information, educational resources and events, for The People and by The People.

FACILITATE

Our role is to enable local communities through ideas, information and support, to serve their needs without 'top down' interference.

COLLABORATE

All of our resources are made possible through the kind collaborations with experienced and skilled members of the PA community.

Our Mission:

To create an integrative healthcare service at community level that empowers people to take responsibility for their own health and is affordable for all.

Our Vision

To facilitate the creation of a network of independent, integrated community health hubs that work collaboratively to empower and educate people to take responsibility for their own health.

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About this Resource

This free resource is a collaboration between The People's Alliance and The People's Care Watchdog (PCW) which works to empower families in the care system. PCW was formed by a group of families to support each other in navigating the care system and they campaign for new systems of care for the vulnerable in our society.

PCW are working to stop neglect and abuse, to empower families in their options and rights, and to show how we can all help create the changes that are needed.

When someone you know and love needs more care and support, there are important things to understand in order to ease your journey through the social care system.

This guide offers practical advice written by families who have navigated the care system. It shares valuable knowledge that we wish we had known from the start.

We hope to equip you with information and resources on how to best look after your loved ones and yourself.

Key points covered in this document:

- Comparing care at home to residential care
- Practical resources to help round the house
- Things to ask and look out for in a residential home
- Self-care and wellbeing
- Dementia resources to empower you and your loved one if a diagnosis is given
- Case studies and testimonials from individuals who have experienced different options for care of their loved one
- Next steps - including space for your notes

#wecare



www.PeoplesCareWatchdog.org

Choosing the Right Care

Navigating the UK care provision

When someone you know and love needs more care it can feel overwhelming. If a time comes where you need to consider professional Care options for a vulnerable family member, the decision can be fraught with concern and emotional weight. Of course, you wish to prioritise their safety and health, while also ensuring their quality of life .

Practical steps can be taken toward choosing the most appropriate and least disruptive Care provision to suit your loved one. Importantly, this process can help you gain peace of mind for all family members involved, safe in the knowledge that sufficient homework and due diligence has been completed.

This guide provides a collection of suggestions, experiences, and resources to consider. All are offered by families who have already navigated the UK Care systems for their vulnerable loved one.



Tick off these steps as completed:

Understand the needs of your loved one

Care support and facilities often specialise in certain types of care, so understanding specific needs helps to narrow down choices.

Research and shortlist support/facilities

Search online, via local councils, Care Quality Commission Website (CQC), and gain insights from your network, friends, family and health care professionals for a rounded picture.

Meet or visit your shortlisted options

Gain crucial insight that cannot be obtained through credentials, websites or brochures.

Check accreditations and reviews

The Care Quality Commission (CQC), provide ratings to indicate standards are being met. However, in 2024 CQC was effectively placed under special measures due to failings.

Assess engagement levels and activity

A good care provision should include a range of activities that meet client's needs both mentally and physically.

Review policy and communication

Effective and open communication channels between family and care staff are essential. It's crucial to understand how care service policies such as The Visiting Policy might impact your loved one.

Understanding costs

Include any additional costs that might be incurred for extra services. Is there a single fee or will you receive itemised charges?



Considering Care Options

While your loved one is at home, you can ask your GP for a social worker to be allocated to them. Social Services can help with equipment, financial support and guidance on how you can access 'direct payments', carers allowance and/or attendance allowance.

Due to the financial model many private care homes operate, staying at home with private carers can work out as a cheaper option. In residential care you are paying a large percentage for accommodation and food.

Bringing in private carers (with financial support from your local authority through your social worker) has also given families the ability to oversee and influence care and make sure needs are being met. Families within the People's Care Watchdog have found that bringing loved ones out of residential care and back to their own home has resulted in marked improvement in their health.

When considering a residential Care Home, it's important to know that there are some great care homes in the UK and there are others that aren't. So, you need to do some homework. You and/or social services will be paying between £600- £2000 a week for a care or nursing home. So, you absolutely should expect adequate staffing levels, professional communication and excellent care.

In this section we offer guidance in three areas:

1. Questions to consider regarding care at home
2. Questions to ask any Care Home or Nursing Home you are considering
3. Warning signs to look out for in Care Homes or Nursing Homes

Care at home



Is it possible to adapt my loved one's home so they can stay there?

- Ask the GP or social worker to refer you to the local Occupational Therapist (OT)
- OTs can provide adapted cutlery and cleaning equipment as well as handrails, specialist beds, commodes, hoists, chair lifts and bath or shower seats
- There could be a frustrating wait for such a referral. Second hand items are usually available for free or cheaply online from places such as Freecycle, Ebay or Facebook Market Place
- A Disabled Facilities Grant (DFG) may be available from your council to cover adaptations
- Entry ramps and accessibility aids such as rest seating and threshold strips or ramps
- Mobility aids eg walking sticks, frames, scooters

- Declutter and remove all tripping hazards such as rugs
- If necessary remove furniture barriers or provide furniture touch points for support
- If going up stairs is an issue consider bringing their personal effects downstairs, or creating a downstairs bedroom
- Keep commonly used items on view so they can be found easily and don't put them in low or high cupboards
- Consider home help for cleaning and meals
- Consider carers for personal care
- Explore DBS vetted volunteers from community groups and churches for extra company



What about dressing and personal care?

- Your loved one may struggle with aches and pains which affect their mobility
- Front opening clothes are easier to put on than anything that has to be pulled over the head
- Shoe-horns are also useful, longer handled versions help with those who struggle to bend down to their feet
- Encourage your loved one to eat by joining them for meals. Consider taking them shopping for food that they have an appetite for
- Check in with them about regular bathing and if they experience any difficulty
- Ensure that your loved one has regular dental, hearing and eye checkups scheduled and help them to attend

"In hindsight, I wished I'd kept my Dad at home despite being encouraged not to do so by social services. There are full time carers that can be employed privately. Do not be coerced into thinking that your loved one will be safer in a care home. I found my father was falling more dangerously in the care home than he had been in his own home."

Is there additional support available?

- Explore local DBS vetted volunteer groups for home assistance like shopping, driving to appointments, or meal preparation
- Churches and community groups can often help. If an internet search proves unfruitful, consider posting a notice in the local post office, library or supermarket asking for DBS vetted help with care
- Meet and interview anyone who you will be trusting with your loved one's care. Ask questions that will explore their experience and competency relative to your specific circumstances
- Trust your gut instinct. You can install cameras in your loved one's home to keep an eye on them when you're not there
- If care needs increase, you can look into employing full time carers. Direct payments can be organised through social services to help with costs. More information can be found in our financial and legal resource linked on page 10
- When choosing live-in carers, ask around and if you can get a personal recommendation all the better
- An internet search will also come up with providers, who again would require interviewing and vetting

Residential Care & Nursing Homes

Residential homes may be run by local councils, voluntary or charity organisations, or private companies. The vast majority are owned by private equity firms who are legally bound to increase profits for their shareholders. Unfortunately if profit is priority, cost cutting can take place through a reduction in services provided, including low staffing levels.

Being able to visit anytime is vital in ensuring the wellbeing, safety and good standards of care for your loved one. If you are concerned at any point about standards, raise these issues immediately with the care home manager, and also inform any assigned social worker.

You should be able to pop in at any time unannounced. If you are asked to make an appointment this is against The Mental Capacity Act which acknowledges and protects those with memory problems or dementia.

Restricting visiting for *any reason is against the law* as it is not 'the least restrictive option'. The care home is now your loved one's home and they must have access to their family and friends as they would when living independently. This includes younger children and house trained family pets.

If your concerns about care standards are not being fully addressed, it is necessary to raise a 'safeguarding' issue with social services. You can contact the local authority safeguarding team directly yourself through an internet search of 'Safeguarding in [name of your local area]'.



Things to Consider

Monitor the staffing ratios

- What is the ratio of permanent and agency staff?
- How many staff can you see on duty?
- What are the staffing levels at night?
- Are they able to adequately perform their duties, and respond to residents?
- Can they communicate clearly in your loved ones first language?

Speak to different staff members

- Are they happy working here?
- Are they supported or over-worked and understaffed?
- Do other staff clean and do laundry or is this expected of the care staff too?
- What is staff handover process from day and night shifts?

Notice other residents

- How do the other residents look & seem?
- Do they show signs of dehydration?
- Are they warm?
- Are their clothes clean and fitting?
- Are they stimulated?
- Speak to residents and their relatives

Ask about physical and mental activities, and access to outdoor space

- Can residents access a garden easily?
- Do they receive daily fresh air and sunlight?
- Are they taken outside?
- Do they offer group activities and day trips?

Nutrition and hydration

- What food is offered at mealtimes and during the day?
- Are residents given help to eat and drink throughout the day?
- Those with dementia and memory problems need help with eating and drinking, requiring adequate staffing
- Do staff monitor and document daily food and fluid intake?

Ask how medicines are stored, prescribed and dispensed

- Is this a care home or a nursing home? Care homes do not have a resident nurse, while nursing homes do
- Consider if/what medication is required
- How is medication given out?
- Who is responsible?
- Do doctors visit in person?
- Are sedatives given? Any sedation must be legally prescribed, monitored, and documented

Ask what other services are made available

- Dental
- Vision and hearing
- Chiropodist
- Physiotherapy
- Hair dressing
- Mini shop for essentials
- Mobile shop for seasonal clothes

Warning Signs To Look Out For

There are quality care homes across the UK that are well resourced, have service user centered policies, and employ staff who truly put their residents at the heart of all they do.

Unfortunately, due to the profit structure of private equity run care facilities and the recent exodus of staff, there are also some very concerning trends that need our attention.

Generally, the structure and reporting within the Care sector is unnecessarily complex and obscure, with Care and Nursing Homes being directly accountable to Local Authorities. In this context, and since lockdowns, issues with staffing levels and also medical coercion within hospital and care settings has risen.

Lockdowns highlighted how vital family support is in keeping the Care system running efficiently and effectively. It is essential to stay informed of any draft legislation that could restrict visiting rights. Endeavour to maintain regular presence in a care home and advocate where necessary.

Nursing Homes must have a qualified nurse on duty in order to classify as a 'Nursing Home'. Care homes do not have qualified in house medical staff. Regularly ask to see your loved ones notes, medical records and MAR charts (Medicines Administrations Record) to see what medication they are on.

All medications can have unexpected side effects and many sedatives are not advised with dementia but are still prescribed. If your loved one is sedated, they will struggle to be enthusiastic about food and drink which can lead to deficiencies such as low potassium and water infections. These in turn can lead to agitation which again can be incorrectly medicated by sedation.

End of Life sedatives (such as Midazolam) are strong medications often used in the last few days or hours of someone's life to help ease anxiety or pain.

Unfortunately, in recent years End of Life medication has been routinely prescribed as 'PRN', (pro re nata) which means 'as required'. It may also be described as 'just in case' medication. This means that using the medication is then left to the discretion of the nurse or team on duty.

End of life medication should always be fully explained and agreed with the patient and family before it is started. If you notice Midazolam, Morphine, Fentanyl or other opioids on your loved one's records without your knowledge this is an indication that an unlawful End of Life Protocol has begun.

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Your loved one can document their own wishes for the future. An Advance Decision (AD) is a legally binding statement detailing what medical and health care treatment they refuse should they lose mental capacity. Family can also arrange to retain responsibility through a Lasting Power of Attorney (LPA) for health and welfare.

If you do not have LPA then decisions about your loved ones health and welfare become the responsibility of your loved ones care team. They must consult with you, but they do not have to follow your wishes. However, they must follow any Advance Decision.

Insist on seeing your loved ones care plan. A good facility will involve those close to the resident when creating the care plan.

Do Not Resuscitate (DNR) orders have become an issue. During Lockdown many older people or those with complex needs had DNRs placed on their medical records without their consent or even knowledge. They can be added to records as 'ReSPECT' (see acronyms).

"As far as possible stick with your own family doctor. Don't be too eager to go with the care home doctor. It's your loved one that matters and the care home is being handsomely paid."

These advanced care plans are sometimes signed under duress, without full understanding of what they entail or without a mental capacity assessment.

LPA for health and welfare gives you ultimate authority in these situations. Without this you can still ask for a 'Best Interests Meeting' to discuss your concerns with social workers, care home and doctors.

Any concern about medication should be raised immediately with the Manager, GP, District Nurse and social worker. Ask if a doctor visited your loved one in person and assessed them face to face. Be polite and firm, and ask for the root cause to be investigated.

If you feel like your concerns are not being heard, you can inform the GP and manager that you will hold them personally accountable if they go against your wishes. Put this in writing.

Your loved one has rights.

Other Options to Consider

- Assisted Living: Independent living in a house or flat with with staff on call 24 hours a day
- Dementia Specific Care: Live-in care at your own home or a Care Home with specialist dementia trained staff
- Explore our Care page for more collaborative ideas at www.the-pha.org/care

Care Comparison

Care at Home

Less upheaval and change

Maintain independence

May create better health outcomes

Private professional care visits at the frequency and hours requested

Option for live-in private professional care

Social Services may help with equipment and finances

Possibility of some physical adaptations or remodelling to your loved one's home

Familiar layout of home and treasured items at hand - beneficial for dementia and well being

Option to install cameras to monitor

Emergency alarm systems available in bracelets, necklaces, or mats to offer reassurance

A social worker can be allocated for individual support

Can work out more cost effective

You and your loved one have more control

Local community support groups may offer additional support

Takes time and effort to set up, organise and manage on an ongoing basis

Care & Nursing Homes

The care or nursing home becomes their home

May be a more social environment with other residents to interact with

Family, friends, children and even pets should be free to visit without prior agreement

The care home decides the policy for activities, access to the outside, food, on site services, meals, and bedtimes

If profit focused, this can reflect in policy and delivery of care

Costs range from £600 to £2,000 per week which is paid for via social services or sale of your loved one's home

Staffing ratios are managed by the Home

General housekeeping and cleaning may be added to care staff duties, meaning less time available for residents

Residential homes use agency staff who may not know the residents very well

Nursing homes must have in-house medical care

Care homes do not have in-house medical care although they may have a scheduled provision

It is possible that their room may be changed or they are asked to move to a dementia 'wing' if their symptoms progress



Case Studies

Mrs D whose father was in a Care Home

"If something doesn't seem right trust your instincts. Act immediately if your loved one tells you that a member of staff is not behaving well towards them. Notice if residents seem nervous of members of staff. If you are concerned, consider hiding a camera or recording device – this has alerted many families to neglect and abuse.

If you aren't happy about a room change the care home wants to make, say no politely and firmly. Be wary if a care home doesn't want you visiting at meal-times. If you don't understand terminology that the care home staff are familiar with ask them to explain or provide details before you feel pressured into any hasty decisions on abbreviations like Dols or DNAR.

Remember you know your loved one better than any of their staff. Don't let them railroad you. If lack of communication or decision making is concerning you, record meetings using audio or video on your phone."

Mrs B, Lecturer in Dementia and Resident Relative

What would you want to ask a care home before placing a loved one?

"These issues are very close to my heart as I have witnessed the devastation of ineffective care... rewarded by a Good CQC rating."

-
- | | |
|---|---|
| <ul style="list-style-type: none">• Have staff received dementia-specific training from a dementia specialist?• What expertise does management have in managing dementia care?• Do management access ongoing dementia-specific training, attend seminars, etc where they can be empowered with correct and up-to-date research and development. | <p>Too often care homes leave dementia care training to people who have read up about dementia, and refer to dementia as a disease. They frequently use derogative terminology (such as "challenging behaviour", when in fact "behaviour" in dementia care is most often a form of communication. Or, they refer to someone with dementia being "aggressive" when it is out of frustration that his / her needs are not being met. I've worked in care provisions where the most senior members of staff did not have a clue, but no efforts were made to change the status quo. They were happy to proceed with great ignorance.</p> |
| <hr/> | |
| <ul style="list-style-type: none">• What activities will my parent or loved one be engaged in?• Can I see the activities calendar / programme?• Also, can I turn up during activities to take part and see how my loved one engages? | <p>In many care homes it is the norm for residents to be left in front of the television for hours on end, with no mental, social or spiritual stimulation.</p> |
| <hr/> | |
| <ul style="list-style-type: none">• How are care staff involved in the delivery of activities? | <p>Too often this is left to "an activities lady" who has to provide stimulation to several people. With the best of intentions it is impossible if you are working with a group with complex needs.</p> |
| <hr/> | |
| <ul style="list-style-type: none">• How will dad be encouraged to maintain a sense of occupation? | <p>Do they use work history, hobbies and interests to help develop care plans, so that the person with dementia can still do what they enjoy, and add meaning to their day?</p> |

Mrs B, continued

-
- How is management involved in the day-to-day service delivery?

Most of the time management is behind closed doors which means they risk not knowing one resident from another. They are tasked with budgets and bringing more people in. I have witnessed many managers who don't engage with the very people who are keeping the home going and helping to pay their salaries and bonuses!
-
- Can my loved one go to bed and get up at a time that he/she chooses (practice her normal sleep pattern?)

In many cases, care homes have agreements in place that (x) number of people need to be in bed before the night shift staff start / get (x) number of people up before the day shift starts. And then they place people in front of the television, where they carry on sleeping until their breakfast is served.
-
- What warning signs should family members look out for?
 - Institutionalisation such as going to bed/getting up at a time determined by staff.
 - Lack of cognitive stimulation and social engagement which speed up the decline caused by dementia.
 - How staff engage with one another - teamwork makes the dream work.
 - Are there factions amongst the staff which impacts on the quality of care?
 - How do management engage with staff?

"I have witnessed too often a top-down approach where management call the shots and care staff are expected to do as they are told. The staff are the best ones to provide input on how individual care should be undertaken. I usually refer to care staff as the eyes and ears of the organisation as they are the ones who spot any changes in individuals first and they are also the ones who can provide input on resources needed to enhance the efficacy of care."

Mrs M, Mother in a Care Home

What I wish I'd known

- Ask right at the start what the home's standard ratio is between staff and residents. Monitor whether the ratio is correct when you visit. Keep notes if not.
- Have a list of questions to ask the Manager prior to accepting the place. Make a note of the answers. That way, they cannot deny that the questions were raised prior to entry.
- If **your** loved one would prefer only to have female or male staff providing personal care ensure that this question is raised and the answer recorded.
- Hopefully the Home will ask the relative to provide background notes about their loved one, regarding family members, hobbies, food likes and dislikes etc but these should also include detailed information about their health issues and any known medication they are taking, together with any side effects which have already been noticed by the family.
- This is important, as it is possible that your relative may be offered a new GP. Having provided a full account of the medical history, medication and known side effects, the relative can then follow up with the GP and staff nurse/carers. Ask for confirmation that you will be informed prior to any change or additional medication being administered to your loved one.
- Ask if the care home has a clothes labelling system. It's essential to label the clothes/underwear which would be sent to the in-house laundry, before the relative moves in. Keep a log of all items of clothing and valuable jewellery and check it sporadically.
- Notice any bruises. Elderly people can develop Senile Purpura which makes them subject to regular bruising. It is a minor trauma. You can buy arm protectors which can help to protect the arms of people with very fragile and sensitive skin. However, some bruises can be linked to falls or collisions with stationary objects. These should always be reported and well monitored by the staff.
- Bruising can also indicate underlying health issues or be a result of poor handling during personal care or seat transfers. If this is the case more training for the staff concerned is required and if such a pattern emerges then this needs to be reported as a complaint. Bruising should always be reported to the GP and monitored by staff and relatives.

About warning signs

- It is important that relatives monitor any mood changes in their loved ones after moving into Care. Initially, it is essential to give positive encouragement and time to try to settle in. Most people are understandably upset at losing their independence but feeling that they are not getting the help they need in their new home is not acceptable.
- Document when the loved one reports being lonely, staff not coming to help them when they ring the bell for assistance, being hungry or feeling sad or frightened. If a pattern of neglect of care is spotted, it needs to be reported.
- It is important and helpful for relatives to keep a diary of the conversations when they visit, so they can identify if there are topics of concern raised regularly by their loved one. When this occurs, it is important to raise the issue with the staff and to monitor the situation on future visits to ensure the issues raised do not increase or become more serious.
- Many Care Providers live in fear of being sued by relatives. When complaints by a relative are made it is important for them to have as much detail and evidence as possible to present at a Safe Guarding investigation.
- Most Care Homes will bring in Regional Managers to undertake a review of staff involved with the complaint incident. I have experienced managers being experts in denying facts and in making this experience your word against theirs. If the relative has kept a diary each time they visit, their notes are likely to be fuller and more accurate with detail and timings.

Gio, PHA Team Member & Family Carer

Advocating for my brother

My brother James is severely autistic, deaf, non verbal and also suffers from psychosis. He is resident in a care home that specialises in caring for residents with certain mental vulnerabilities.

He is on DoLS (Deprivation of Liberty Safeguards). DoLS are rules in the UK that ensure people who can't make decisions for themselves are looked after safely and have their rights protected. These rules apply when someone needs to be cared for in a way that restricts their freedom, like being in a care home or hospital without the ability to leave. DoLS ensures that this care is necessary and in the person's best interest, and that there are regular checks to keep them safe and respected.

James began to gain a little weight, and over the years, his weight increased to 18,5 stone (117.5kg). Health issues crept in and James began to suffer from painful gout, IBS, and quickly got out of breath. He couldn't tie his shoe laces as leaning forward put pressure on his stomach.

There were two doctors, a toxicologist, a psychiatrist, carers, management from the organisation, and during meetings they all decided that the problem was an unfortunate known side effect of the medication given to James to help him manage his symptoms.

We had one meeting every three to four months where I repeatedly pushed for a dietician to assess his menu and lifestyle. At first his team explained to me why this was not the case and this continued for around 18 months. During this time James's health and motivation declined.

Towards the end of this period I was treated as 'the loving brother' that was being a pain trying to advise specialists how to do their job. I was in fact asking 'what if' it wasn't the food but a side effect of the medications.

My own family unfortunately accepted the specialists view and over time suggested that I let this go. The headaches and stress of dealing with this situation were like nothing I had experienced but I was not willing to drop this.

It got to the point where my brother's care team felt they had tolerated me long enough and failed to invite me to a meeting. I went anyway. In the end, to shut me up, they decided to bring in a dietician for a while - anything to get this irritation (me) out of their hair.

The dietician worked with the staff and care team to manage James' menu and gradually remove some items that were very bad for him. As anyone working with autistic people knows well, they do not often tolerate change, causing many other issues that upset them, so we worked very slowly, in baby steps.

Advocating for my brother, continued

Admittedly, James was not too happy, and as he could not hear, was non-verbal, and only understood a few signs (sign language), the changes could not be explained to him. So, the management and care staff ensured these changes were implemented over a two year period.

Over that period James got his health back. His gout and IBS cleared up, he lost four and a half stone, and could breath so much better; he was going for walks with staff two or three times a day and now even the staff were struggling to keep up with him.

The organisation that helps to look after him were so impressed with the changes that they had the dietician work with the chefs across all of their care homes so as to improve the health of their other residents.

Knowing that I played a part in giving my brother a better quality of life is, by far, one of the best achievements of my life.

My experience is just one of many within the People's Care Alliance team. We all have our own individual experiences, and many have a loved one they have stood by and helped for many years.

We do this because we have lived through difficulties and stresses brought on by such situations, and we hope to be able to help others going through such situations. Be it things like trying to find the right sort of healthcare or being pointed in the right direction to get the correct help. We are here and will do what we can to try to make things that little bit easier for you.

I am very lucky to work alongside such an experienced and caring team, and knowing that we are striving for something better.

Lisa, PHA Team Member & Family Carer

For the love of Ivy

My lovely Mum, Ivy, was diagnosed with Alzheimer's in 2012, aged 81. Dad had passed away 9 years earlier and Mum was still living in our family home in North Manchester. At that time, I had a young family and a growing business, but I managed to travel the 70 mile round trip 3 or 4 times a week to see Mum and she had a couple of good friends/neighbours who kept a close eye on her.

By 2014 Mum was finding it increasingly difficult to stay on top of daily tasks such as cooking and cleaning. I knew that we needed help and quickly realised I had no idea where to even begin! All I knew was I had to do everything I could to keep Mum at home and relatively independent for as long as possible.

I found a local company providing care at home, something that Mum was not happy about! Like so many of us, Mum was fiercely independent, stubborn and very proud - accepting help did not come easy. Fortunately, her carer Irene understood this and worked hard to gain Mum's trust, eventually forming a friendship.

At the same time, a friend who was a Financial Advisor recommended I look at putting in place Lasting Power of Attorney's for Health & Welfare and for financial matters. I'm very grateful for this advice as it allowed me to make decisions for my Mum that were in her best interests when she was no longer able to. I was also advised to make sure Mum's will was up to date with her wishes and to look at a Family Trust for the property. In hindsight this advice proved to be very valuable in navigating the Care System but sadly it was not readily available, rather, it was stumbled upon.

The at-home Care worked for a while and between Irene and me we managed, always conscious of keeping Mum as safe, yet independent, as possible.

In early 2015, the disease had progressed and things took a turn when Mum had several UTIs which culminated in her being found wandering the streets, some way from home and horribly confused. This landed her in hospital, at which point social services got involved and decided that Mum couldn't be discharged to live at home alone.

This is when we made the very difficult decision to find a Care Home for Mum, one that would provide not only the care she needed but also the company she deserved. I feel that social interaction is crucial to slowing down dementia and I wanted to make sure Mum was surrounded by people and activities.

I insisted that the Care Home be close to me so that I could visit every day...I would not let my Mum feel abandoned, not for one second! This decision was probably the hardest one I've ever had to make and it is one that carries with it a lot of guilt. A bit like being a Mum, you never really know if you are doing the right thing, you can only trust your instincts and pray that you are.

For the love of Ivy, continued.

Finding a suitable place was not easy. On the CQC website (www.cqc.org.uk) you can search Care Homes in your area and view their inspection reports and ratings, similar to school Ofsted reports. Unfortunately, many are outdated, some three years old, in which time things can change a lot. But, it was a start and it enabled me to shortlist a number of places to investigate further.

Next step was to ask friends and colleagues who had experienced a loved one going into a Care Home and getting a feel for those on my shortlist. My list got shorter and on enquiring about availability, it got shorter still! In the end we had three to visit and one quickly stood out to be as being 'the one'!

From the day I stepped into Belmont I liked the feel of the place - it wasn't plush and perfect, yes it could've done with a lick of paint in places, but it was homely and the staff, from kitchen to Carer to Management, were welcoming, open and chatty. I talked with other residents and observed how the carers interacted with them. I really liked that they wanted to know everything about Mum, her likes, and dislikes, about her family, her medical history, and her personality traits. Whilst I was trying to figure out if they were the one, they were trying to decide if Ivy would fit in with them and all they had to offer. I loved that they had Mum's best interests at heart from day one.

In March 2015 Mum moved in and true to my word I visited pretty much every day. The staff and residents of Belmont became mine and Mum's extended family over the years that followed and I quickly realised we had been very lucky to find this place. My visits were always unannounced and at all times of the day, such is the way when juggling children and work! I'd pop in for breakfast with Mum or after work for a brew and occasionally to tuck her up at night. And the care was always consistently good - she was clean, well fed and happy (to the extent that this cruel disease allows). She was safe.

Things I loved about Belmont:

- The carers, who really did love the residents
- The residents - lots of different needs, challenges, and characters but all loved
- The many activities and trips out, made available to all
- The fast response to any health concerns I had
- The open door policy - I could visit any time of the day and night.

Mums condition continued to deteriorate and by autumn 2019 she was more or less bed-bound. Then came the Lockdown. This changed everything - I was no longer allowed into the Care Home but wild horses couldn't have stopped me from keeping my promise to be there every day. For 9 months I watched at Mums window, her unable to know I was there and me breaking my heart as I feared she thought I'd abandoned her. All I could do was keep on top of her wellbeing through regular contact with the carers and the GP practice, whilst making sure she was not subject to any unwanted/unnecessary medical interventions. This is why LPAs are so important.

For the love of Ivy, continued.

By December 2020 I could see from my spot at the window that things were not good. I insisted that I be allowed in but my request was declined due to their Covid Policy. At this point I'd just about had enough and informed the Care Home management that if my Mum passed away without being with me again, I would sue everyone involved. The next day I was granted permission to visit.

This taught me a valuable lesson in life, to do your research, understand your human rights, and where possible make those putting barriers in your way know that you are empowered and that they could be personally liable for poor decisions they make.

Six days later Mum passed away. I spent those last six days with her, holding her and telling her how much I loved her. I told her I'd never left her, that I was always there. I hope she knows, they say that hearing is the last of the senses to go, so I hold that in my heart. Mum must've weighed 4 and a half stone by the time she went and it was almost a relief to see her free from this cruel disease.

I remain grateful to Belmont for the love and kindness shown to my Mum and me over the almost six years she was there. When Mum and I started our journey with Alzheimers I didn't have a clue where to begin looking for support. It really was a minefield; from dealing with Social Services, setting up LPAs to protect Mum's best interests, to finding at-home care and ultimately residential care.

This is why I am part of The People's Health Alliance Care team. It is so that I can help others who find themselves in a similar position, to navigate the system by providing resource packs and signposting them to advocacy services who can help when things don't go to plan.

Knowledge is power and it is time that we all take back that power to make sure our loved ones receive the care they deserve. We also need to come together in our communities to transform the way we care for elderly and vulnerable people, creating solutions that are patient-centric, and focused on prevention and proactive monitoring.

Acronyms

Below is a list of the most frequent acronyms which you may encounter in engaging with a Care Home or Local Authority Social Services. We hope these will help you to feel empowered.

ACRONYM	MEANING
ASC	Adult Social Care
BIA	Best Interest Assessment
BIM	Best Interest Meeting
CCG	Clinical Commissioning Group
CH	Care Home
CHC	Continuing Healthcare
CHM	Care Home Manager
COP	Court of Protection
CQC	Care Quality Commission
DBS	Disclosure and Baring Service
DNR	Do Not Resuscitate
DNR & DNAR & DNACPR	All mean do not attempt cardiopulmonary resuscitation. So, if heart or breathing stops, they will not try to restart either of them.
DoLS	Deprivation of Liberty Safeguards
DSARs	Data Subject Access Requests
DST	Decision Support Tool
EPA	Enduring Power of Attorney
FOI	Freedom of Information
GDPR	General Data Protection Regulation
IMCA	Independent Mental Capacity Advocate
LA	Local Authority
LPOA	Lasting Power of Attorney
LPS	Liberty Protection Safeguards
MCA	Mental Capacity Act
MHA	Mental Health Act 2005

NAME	MEANING
NoK	Next of Kin
OPG	Office of Public Guardian
POA	Power of Attorney
SAR	Safeguarding Adult Review
SALT	Speech & Language Therapy
SARs	Subject Access Requests
SW	Social Worker
PRN	Pro re nata (medication given as and when 'needed')
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment.

Dementia Resources

Initial Resources Upon Receiving a Diagnosis

For an uplifting and positive first exploration after a dementia diagnosis, consider watching this film narrated by Michael Bubl : <https://memoriesforlifefilm.com>

Dr Dale Bresden and his books give hope to prevent, slow down and even in some cases reverse dementia: <https://www.apollohealthco.com/dr-bredesen>

Dr Gar Chalfont provides UK based dementia coaching based on the Bresden protocol.
Email: dementiapioneers@gmail.com

Patrick Holford has spent 40 years researching illness prevention including memory loss. <https://foodforthebrain.org/the-cognitive-function-test>

Recommended Books on Dementia

- From Dementia to Rementia by Jackie Pool
- The end of Alzheimers by Dr Dale Bresden
- Dementia Positive by John Killick
- Dementia: Support for families and friends by Dave Pulsford and Rachel Thompson
- Contented Dementia by Oliver James

Training Available for Family Members

There are often carer education programmes within your local authority. These include advice on many practical things such as:

- understanding dementia
- benefit advice
- Lasting Power of Attorney (LPA)
- looking after yourself
- dementia friendly activities
- responding to difficulties and changes in behaviour

The Alzheimer's Society delivers these in many areas but it is worth investigating who holds the 'Dementia Navigator contract' in your local authority. <https://www.alzheimers.org.uk/about-us/our-dementia-programmes/carers-information-support-programme>

In some areas there are education programmes for people diagnosed with dementia, delivered by people with dementia: <https://www.dementivoices.org.uk/wp-content/uploads/2015/04/AGLWD-the-statements.pdf>

Support Services & Groups

Carer Support Online (Dementia Specific)

Together in Dementia Everyday (TIDE) offer a wide range of support and helpful resources:
<https://www.tide.uk.net>

Carer In-person Support Groups

Local groups are available to help people with dementia. The DEEP network is a great example of this: <https://www.dementivoices.org.uk>

Support Groups for People With Dementia

Groups are available in some localities. They help people with dementia in different ways; to accept their diagnosis, to give them hope, to socialise with other people with a diagnosis, to support one another and have fun. <https://www.dementivoices.org.uk>

Dementia National Support Helplines

- Alzheimers Society Support line for a wide range of help: <https://www.alzheimers.org.uk/about-us/contact-us>
- Admiral Nurse Helpline for family care partners in need of advice, especially in complex or difficult situations: <https://www.dementiauk.org/get-support/dementia-helpline-alzheimers-helpline>

Social Stimulation and Activity Groups

Some people like to find groups, either for the person with dementia to attend alone or to go to together with a family member or friend. To find out what groups are available locally it is worth getting in touch with whichever organisation holds the 'dementia navigator' (or equivalent) contract with your local authority. Age UK can also be helpful or the local Alzheimer's Society.

Factsheets On Dementia Related Topics and Caring

There are many factsheets on dementia related topics available in the UK online. They cover many topics from Lasting Power of Attorney, benefits, keeping active etc.

- The Alzheimers Society: <https://www.alzheimers.org.uk>
- Dementia UK: <https://www.dementiauk.org>
- Independent Age: <https://www.independentage.org>

Management & Therapies

Cognitive Stimulation Therapy (CST)

The National Institute for Health and Care Excellence (NICE) recommends CST for people diagnosed with dementia. The timing is important and there is an optimum time during a dementia journey. CST is available in some localities and is delivered in different ways. Some services offer a 10 week programme, other offer an ongoing maintenance programme. Find out more here: <http://www.cstdementia.com>

GREAT Cognitive Rehabilitation (CR)

NICE also recommends CR for people diagnosed with dementia. It is most effective in early stages of dementia but can be useful as dementia progresses as well. It is a 6-8 week programme delivered at home with a CR professional. It is not widely available yet but there is a very good self-help resource here: <https://sites.google.com/exeter.ac.uk/great-cr/for-practitioners/elearning-course>

Cognitive Rehabilitation Self-help Resource

This resource has been developed to help people with dementia, help themselves. It is most effective in the early stages of dementia: http://www.innovationsindementia.org.uk/wp-content/uploads/2022/02/My-Life-My-Goals_Workbook_Feb_2022.pdf

Cognitive Stimulation Home Therapy Manual

The manual is a great resource for family care partners. The manual is available to buy in print or online: <https://hawkerpublications.co.uk/product/making-a-difference-3>

Living With Dementia Toolkit

A great evidence-based resource for people diagnosed with dementia and their care partners. The toolkit is extensive covering themes like: staying safe and well; stay connected; keep a sense of purpose; stay active; stay positive: <https://livingwithdementiatoolkit.org.uk>

Quality Activity Resource Suppliers

Lots of activity resources are available to buy nowadays. Here are a few quality suppliers:

- Activities to Share: <https://www.activitiestoshare.co.uk>
- Alzheimer's Society online shop: <https://shop.alzheimers.org.uk/collections/gifts-for-people-with-dementia>

Movement & Memory

Music

It is well known that music can retrieve memories. It can be useful to create playlists for Life.

- Create playlists you love to listen to and reminisce: <https://www.playlistforlife.org.uk>
- BBC music memories has a wide range of music to investigate from their music archives: <https://musicmemories.bbcrewind.co.uk/home>

Fitness and Exercise

It is important people with dementia remain active and as physically fit as possible:

- Find a local exercise class that offers yoga, tai chi or swimming
- British Gymnastics Foundation Love to Move seated exercise programme: <https://britishgymnasticsfoundation.org/lovetomove>
- Dementia specific holidays and resources to help get outside and connect with nature more: <https://dementiaadventure.org>

Life Story Work and Memory Boxes

A great way to reminisce and engage in making something together which can be used again.

- Memory boxes are often multi sensory and can help people with dementia if they are in distress and at other times: https://www.youtube.com/watch?time_continue=126&v=xVDEqXDwKgl&feature=emb_logo
- Life story work can be very useful and engaging for some people with dementia. Some resources exist to help the process of creating a life story record: <https://www.dementiauk.org/get-support/living-with-dementia/creating-a-life-story>

Reminiscence

Reminiscence could be an enjoyable and accessible activity for people living with dementia and their care partners to do together.

- BBC archives have a wonderful library of resources to investigate and reminisce about. They include videos, audio archives and photos from their extensive library over the decades: <https://remarc.bbcrewind.co.uk>
- European reminiscence network. They have done some wonderful projects in the past and an interesting website for anyone interested in reminiscence and dementia: <http://www.europeanreminiscencenetwork.org>
- Sporting memories. Focuses on sporting memories relating to a wide variety of sports. Provides opportunities to reminisce about sport and to join local groups: www.sportingmemories.uk
- Local library archives online

Next Steps

Create Your Plan of Action

First: Visit the PHA and PCW websites for further resources to aid yourself and your loved one.

www.the-pha.org

www.PeoplesCareWatchdog.org

Second: Explore our directories of local community hubs and health practitioners to support you.

[www.the-pha.org / directories](http://www.the-pha.org/directories)

Finally: If you have found this resource helpful, please share it within your circles to help us to help more people at this impactful time in their family's journey.

[www.the-pha.org / resources](http://www.the-pha.org/resources)

Additional Resources

As part of the wider People's Health Alliance community, we also signpost tools that support individuals and families in preparing ahead.

My Medical Choice is one such resource, designed to help people clearly document their healthcare wishes and ensure they can be delivered rapidly in an emergency.

www.mymedicalchoice.org



The PHA community has secured a preferential rate for those accessing the service through the link above, applied automatically when the page is opened via this resource.

Your Notes

Your Notes (continued)...



**The People's
Health Alliance**

For The People, by The People

Feel free to get in touch with us for any
feedback or questions.

www.the-pha.org/contact

Email: info@the-pha.org



Read and download the most up to date version of this resource here:

<https://the-pha.org/caring-for-a-vulnerable-loved-one-what-you-need-to-know/>

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