Doing It Well Seven steps to dignity and compassion in caring for older people

Guidance for those who care



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The Beth Johnson Foundation

The Beth Johnson Foundation (BJF) is a national charity dedicated to making 'a future for all ages'. We want everyone to enjoy a great later life, which means we as a society need to make changes at a strategic and practical level. Conducting cutting edge research, advising policy makers, and initiating pioneering age-friendly programmes, the Beth Johnson Foundation is at the forefront of making these changes happen. www.bjf.org.uk

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Doing It Well

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Foreword

his guide reflects one of the central aims of the Beth Johnson Foundation (BJF): to spearhead innovative work and interventions that address some of the challenges facing older people. As the title suggests, its particular focus is on helping those who are directly responsible for the care of older people to do their job as well as possible. It adds to our current work around the care of older people in care settings and complements our recent publication *Experiences of Being*, which outlines the benefits of drama, music and dancing in improving the wellbeing of people in care homes, especially those with dementia.

This guidance digs deeper into the care setting and explores how individuals being cared for can best be looked after, taking account of their individuality, what they think and want, and their feelings. Although this might seem self-evident, too often such concerns are forgotten in the busy and stretched world of care provision.

Our emphasis is on an approach that highlights dignity, compassion and respect – all individual needs of the person being cared for. This approach is also important for the people around them – families, loved ones and friends. These qualities are what most care homes and related organisations want to strive for, but they can be forgotten or neglected at busy times, and may not be seen to be the priority, especially when resources and support are limited.

Our intention is not to be overly prescriptive or critical. While recognising the challenges and pressures that staff face in care settings, we emphasise that what ultimately really matters is delivering care with compassion. We hope this guidance will make a solid contribution to showing how this can be achieved.

Colin Hann, Executive Chair, BJF



Introduction

n an increasingly ageing world it is important to address the fundamental values and attitudes underpinning the care of older people within care settings – whether care homes, hospitals, hospices or domiciliary care. We need to find the balance between good medical practice and compassionate, emotional care.

About this guidance

Doing It Well is intended as a springboard to help conceptualise person-centred care that encompasses dignity, compassion and respect, and as a reminder of how much this depends on seeing the individual inside the person being cared for.

This guidance will consolidate the understanding and practice of compassionate, dignified care, and deeper more effective ways to engage with and positively support staff and residents. It includes emotive and inspiring topics for discussions as well as dilemmas to consider and resolve.

The experiential exercises will facilitate greater understanding of an older person's experience and prompt fresh ways to enrich relationships, purpose and meaning. The suggested activities are simple but offer far-reaching learning potential.

How to use what we outline

Doing It Well suggests seven important steps that will help improve the quality of care for older people. The personal anecdotes and dilemmas included in our guidance aim to help illustrate the real meaning of dignity for all.

Our guidance can best be used as part of a blended approach to learning in the workplace, supported by coaching, supervision and mentoring to ensure that its implementation is sustained. Each step introduces topics that can be expanded upon within your own care setting.

The guidance is intended for use as an integrated resource for group discussion or for individuals, who can take themselves through some of the exercises as an aid to their independent learning. The steps can be used separately and have been designed with a degree of flexibility to facilitate their use in different training situations.

The audience for this will primarily comprise healthcare and social services professionals, managers, nursing staff and care workers – whether working in care homes and hospices or in private domiciliary care. However, it is also relevant to volunteers, non-profit

organisations and charities who work in the sector. We hope it will also be useful to the wider public; many of us may have a close friend or family member entering the world of 'care', and we may suddenly find ourselves needing care.

Step one: Dignity awareness



To engage staff recognition of the importance of dignified, person-centred care and how to assess and improve their delivery of such care. To understand that a person's dignity can be violated or enhanced by our interactions and attitudes.

The word 'dignity' says something very profound about an individual's uniqueness, distinction and inherent entitlement to respect. Our sense of dignity is intimately linked to our sense of what it means to be human and the way we, as humans, treat one another.

Discuss:

- What does being treated with dignity feel like to you?
- Describe a time when you were treated with dignity and respect.
- What does being disrespected feel like to you?
- Describe a time when you felt disrespected, and how it made you feel.

When we look at things from a personal perspective it allows us to engage with older people in a compassionate and more meaningful way. List your answers.

Consider:

When dignity is not present, or is thoughtlessly eroded, the individual can feel devalued, worthless, pitiful, outraged, afraid, withdrawn, lonely, depressed, hopeless and even suicidal.

Research with terminally ill people has clearly shown that a personal sense of dignity, or the lack of it, can literally determine whether a person wishes to live or die. In one study, two thirds of dying people in a hospital setting felt that their dignity could be taken away from them by those who were caring for them.



Discuss:

What does undignified care in a care setting look like?

Examples evident in many care homes and NHS wards today include having the television on all day long; talking over or around patients; rushing mealtimes; leaving vulnerable adults exposed, soiled or without privacy; failing to provide stimulus or meaningful activity.

Such behaviours amount to a culture of institutional and psychological abuse, with staff who may have become task orientated and routine driven, and who do not think, but simply act mechanically, which all works to create a sense of hopelessness and helplessness in people who are supposed to be receiving care in the true sense of the word.

Tip:

To provide a supportive forum for care staff and the sharing of good practice, become a dignity champion. See: www.dignityincare.org.uk



- Have Zero tolerance of all forms of abuse and neglect.
- Support people with the same respect you would want for yourself or family.
- Treat each person as an individual by offering a personalised service.

- Enable people to maintain the maximum level of independence, choice and control.
- Listen to people and support them in expressing their needs and wants.
- Respect people's rights to privacy.
- Ensure that people feel able to complain without fear of retribution.
- Engage with family members and carers as care partners.
- Help people to maintain self-confidence and positive self-esteem.
- Act to alleviate people's loneliness and isolation.

Remember:

A common belief is that dignity is achieved by treating others in the way that you would wish to be treated. Reassess this from a more person-centred perspective, because dignity means treating others in the way that **they** wish to be treated. There may well be differences. One of the best ways to improve your delivery of care is to ask the older person at the receiving end, 'Am I giving you the right level of the support you need?'

Exercise:

In pairs, ask each other the following questions and mark down your answers honestly as **Well**, or **Not very well**. Use your answers as a reflective tool to plan actions towards further improvements. Where you answered **Not Very Well** create a personal action plan each for the other, and make clear **what** you will now do differently, **how** will you do this, and **what outcomes** will be seen in the workplace.

- How well do I keep polite and courteous even when under pressure?
- How well do I see things from the perspective of the older person?
- How well do I listen to an older person?
- How well do I encourage older people to express their needs and wants?
- How well do I control my impatience and frustration?
- How well do I respect the privacy of others?
- How well do I remember to knock before entering an older person's room?
- How well do I ensure that older people are not left in pain?
- How well do I respond to personal care needs?
- How well do I alleviate an older person's loneliness?
- How well do I enable older people to have the maximum level of choice and independence?

- How well do I engage with relatives' concerns?
- How well do I report sub-standard care?
- How well do I assess my own behaviours?
- How well do I respect the roles of all staff members?
- How well do I attend to nutrition and hydration needs?
- How well do I adjust the pace of care according to the different abilities of older people?

Remember:

Respecting each other's roles and using time well.

- If, after use, every item of paperwork, equipment, medicine, laundry, notes and so on, were immediately put back where it belongs, how much time do you think you could save?
- So, being respectful and mindful of putting things back where they should be means that staff will have considerably more time to be with residents.
- Be honest with your residents about timings, or you will lose their trust very quickly. So rather than saying that you are going to be back in five minutes when you know you won't be, adjust your words to, 'I will be back as soon as I can.' If you continually break your promises, you erode your own self-esteem as well as the trust of residents.
- Imagine that you are short staffed, with call bells are going off left right and centre, how can you make the person whose call bell you are responding to feel that they are as important as everyone else? Being centred, focused and calm with an older person helps them to stay calm and also to keep greater clarity about what is happening. Use your time well. Tell the older person, 'I may only have two minutes, but for those two minutes I am all yours. How can I help?'
- It is better to be fully present with an older person for two concentrated, purposeful minutes than to be with them for five distracted ones.

🔁 Discuss:

How can you make mealtimes a more dignified experience?

Use the checklist below to add to your answers. Remember that eating and drinking are important daily events that should be enjoyed rather than endured:

- Observe the older person's needs and then ask them if they need any help, in a way that does not to rob them of their dignity or sense of control.
- Encourage offering small titbits as a starter an hour before a meal can increase appetite. But gentle coercion must not give way to bullying.

- Foster independence offer an older person jam to spread on toast themselves, or sugar to stir into their tea if they are able. Do not take over.
- Presentation if pureed food is required, consider the creative use of moulds to make the food appear more appetizing. Serve food on a larger plate, so it looks smaller by comparison, to encourage an older person to eat more and not be overwhelmed by perceived portion size.
- Ensure that no childlike bibs are used clothes protectors or large napkins are more dignified.
- Give complete attention silence mobile phones and other distractions.
- Allow enough time feeling rushed not only erodes self-confidence but can force an older person to become more dependent, or to give up trying altogether. Do not load another spoonful before an older person has finished the previous one.
- Tidying up: ensure that an older person has finished before you clear away, and that any messes or spills are gently, sensitively and discreetly dealt with.
- Equipment: consider what might be needed to help someone with painful joints or arthritis. To prolong independence, ensure that you have special equipment such as non-slip mats, or large handled cutlery, to help grip, or a plate with a lip guard for an older person who only has the use of one hand.
- Seating: ensure that your chair is not higher than an older person's, as a higher position can seem intimidating to a frail older person, especially if you are helping them, and never stand over an older person while you help them.
- PEG feeding: If this is not being done overnight, remember that this is the way that individual has their meal. If no consideration is put into making the start of the PEG feeding a special experience, people can easily feel dehumanised. Find out if the older person wishes to start their PEG feeding with everyone else in the dining area. Have you offered the latest mouth wipes that can be different flavours and be pleasurable for some? If starting a PEG feed in an older person's room, can flowers be laid out, with music playing? Ask the individual what they would like.

Consider:

In our diverse society it is important that we all have tolerance and understanding of each other's backgrounds to ensure we maintain dignity and appreciate and learn from cultural differences.

Consider what you can find out about another person's cultural background, and share about yours. Questions to think about might include-

- How might your perception of age and gender differ from others?
- Who is in your/my family?
- What is your/my cultural perception of age and gender?

- What are your/my customs associated with food and dietary requirements?
- What languages do you/I speak?
- What festivals do you/I celebrate and what are their significant dates?
- How do you/I like to dress; are there areas of potential offence?
- What are your/my religious practices, beliefs and values?
- What is your/my cultural attitudes to death and dying; are there any special customs?
- What is your /my attitude towards intimate personal care?
- Is there anything else we would like to share?

Remember:

Ensure that staff know the names of residents but, just as importantly, do the residents know the names of staff? Perhaps the staff have name badges but a resident may not be able to read them, or to pronounce foreign names.

Staff can unwittingly institutionalise themselves by becoming nameless and therefore faceless when they forget to introduce themselves regularly. Not only is it good manners; it will be reassuring to residents.

For those with Dementia, you may need to give prompts of your name more often whilst keeping patient and good natured.

Step two: Recognising ageism



To become fully aware of ageism and its effects. To re-focus staff to see older people as equally valued individuals, and to remember we all hold, right now, the seed of the older person we are to become.

The proportion of older people in the population is rising, so more support will be needed for the continuing care of those who need it, and we must understand the importance of recognising and honouring everyone's intrinsic worth, regardless of age.

Those who are ending their lives deserve the same care and attention as those who are beginning their lives in the helplessness of infancy.

Addressing ageism and changing attitudes towards growing older are necessary steps when placing dignity at the heart of care.



- Does your own fear of getting older or dying prevent you from getting closer to an older person in your care?
- How does this attitude affect what you do and how you respond to older people?
- Are you unable to acknowledge your own age for fear of negative judgements from others?
- What judgements have you heard in the media or in care settings, and what assumptions have you made? Examples might include:
 - Old people have less value in society.
 - Old people don't know what's going on in society any more.
- How can we shift our perspective so that we do not wear old age as a burden but as a crown?



Remember:

Care workers have the ability to restore someone's self-worth and yet many fall into the ageism trap when, for example, they are reluctant to use technology because of an unwarranted assumption that an older person may shy away from it, or when they routinely dismiss physical or mental symptoms, such as aches and pains or depression, as a natural part of the ageing process, without looking for other causes.

Ageism is not only oppressive and humiliating but can become a self-fulfilling prophecy. Negative societal stereotypes can cause older people to view themselves as weak and passive. Studies¹ demonstrate that older adults who possess negative self-stereotypes perform more poorly than others on memory tasks

Consider:

Our society and media often portray older people as grumpy, useless, a burden. The message to younger people is that 'getting old is bad, and being old is worse!' We need to counteract media-influenced notions that equate ageing only with decay and degeneration, by encouraging pride in growing older, promoting an intergenerational life and watching out for any words and expressions that convey a negative view of ageing.

The language we may ourselves use about being 'past it', or 'over the hill' perpetuates negative stereotypes. To free ourselves from the social stigma that such attitudes

See, for example, Levy, B. 'Improving memory in old age through implicit self-stereotyping' in *Journal of Personality and Social Psychology*: December 1996; 71(6):1092-107; and 'Mind Matters: Cognitive and Physical Effects of Aging Self-Stereotypes' in *The Journals of Gerontology*: Series B, Volume 58, Issue 4, 1 July 2003: 203–211.

engender, we have to learn to appreciate ourselves as people whose lives are each an amazing accumulation of lived experiences and emotions. In many other cultures and tribal traditions older people are embraced, revered, and sought out for their knowledge and experience. Grandparents are seen as figures of great dignity, and old age is seen as a highly valued time for the flowering of wisdom.

Exercise:

Take time now to think of an older person who has made a difference to your life, whether by their love, their humour, or a good recipe – someone who has touched you in a positive way. As a society, we are not very good at thanking others, particularly



our older people, often leaving it until it is too late. Please take a few minutes to share your memories and thoughts with a partner or the group.



Remembering someone loved in the above exercise becomes a point of contact and shared joyful remembrance. This helps to break down barriers, and may elicit laughter and tears too. Sensitively acknowledge the pain of remembrance for those who have been bereaved, and remind staff that, when they remember an older person in this way, it becomes easier to view the people in care with a clearer vision, as valued individuals who have been important to others and loved for the difference they have made.

Discuss:

- What older person inspires you?
- What about an older person in your care inspires you and why? Can you tell them? Will you tell them?
- What do you love most about working with older people?
- What inspired you to work in care?



The following words from an 82-year-old Mr Clayton:

The longer you survive, the more you rely on yourself. But I had a leg amputated, and so I had to come into this care home place. I thought, well, I've still got one leg. So I pushed myself around in my wheelchair with my foot. But they still couldn't stop trying to help – shoving me from one place to another when I was doing all right on my own. Lots of bright smiles, but they just weren't listening. Then I blew my top and shouted if Douglas Bader could fly a Spitfire war plane with no legs, I could push a wheel chair with one. But they listened in the end. And do you know, I have never had any trouble with the carers since. They are a good crowd really, once they listen. It might take me a long time to get to supper, but it works up an appetite.²

² Amanda Waring, *Heart of Care*, Souvenir Press, 2012, and *What Do You See*? DVD training pack (self-published), 2009.

Step three: Understanding dementia



To inspire greater compassion and better person-centred care through understanding the experience of someone with dementia.

Carers need to try to enter into the world of people with dementia, who are often withdrawn into their own reality. Medication has historically been used particularly for people with dementia who have complex issues including aggression, shouting, delusions and psychotic symptoms.

However, it is important to remember that such behaviours may result from communication difficulties and misinterpretations of needs by both the care worker and the older person. It has been argued that powerful sedative drugs are widely used too early, and can have serious negative side effects. Undetected, underlying emotional needs that require careful and dedicated unravelling may identify a cause of the agitation, and a way of releasing it.

Consider:

Try to walk in the shoes of a person with dementia, to understand as fully as possible the challenges and stresses they face, and the positive steps from this awareness that you can take to support them.

If I had dementia

- I might slow down with my conversation, I might repeat myself.
- I might confuse the past with the present reality, I might find myself dwelling in the past and fretting over past experiences.
- I would like a carer who can be patient and can reassure me in the present moment, but can also 'time travel' with me – not make me wrong, but understand my feelings.

If I had dementia

- I might experience mood swings and aggressive outbursts.
- I would like a carer who can be aware of the nuances of my behaviour, and can recognise if I am in physical or emotional pain, or both.



If I had dementia

- I might have problems communicating my thoughts and feelings. I might not understand what is being said to me, or what is going on around me, and I might feel disorientated. I might not be able to convey much information.
- I would like carers to remember that verbal communication is only one way to communicate; there are other ways. I would like them to take time to observe my expressions and body language, and take clues from that as to how I may be feeling.

If I had dementia

- I might feel frustrated with visual or hearing impairments.
- I might have a fear of falling or of having accidents.
- I might feel anxious and isolated, and withdraw from involvement with activities.
- I might be uncooperative.
- I would like carers to persist in trying to 'reach' me, and to give me emotional and practical support to maintain involvement in my interests and hobbies – those within my capabilities.
- I would like to be included and gently coaxed into positive social encounters. I would like carers to see the underlying reasons behind my behaviour before resorting to medication.³

³ Adapted from Rosemary Hurtley, *Insight into Dementia*: Waverley Abbey Insight series, Age Concern Books, 2008.

Tip:

When communicating with someone with dementia, providing a running commentary can improve their ability to navigate and orientate themselves. Remind them of what has just happened. Tell them what is happening now and what is about to happen. Use simple but clear language. It is important to ensure that eye contact is made before any personal care takes place.

Exercise:

There are very good sensory deprivation tools to enable carers to feel what it is like to have certain impairments, thus increasing empathy and understanding. Consider trying this simple exercise too:

Working in pairs, one of you is blindfolded and takes the arm of their partner, who guides them slowly around the room, where several obstacles have been placed. The seeing partner will then step away and only give verbal instructions for the blindfolded person to follow: 'Turn left', and so on. Take it in turns to navigate the room blindfolded and discuss with each other:

- How easy did it feel to be reliant on someone else?
- How easy was it to trust that person?
- How vulnerable or supported did you feel?
- Given your understanding of walking in another's shoes, will your perceptions and tolerance levels change?⁴

Exercise:

Using memories as medicine:

For someone with dementia, focusing on distant memories can sometimes be a means of escape from pain or anguish, or a coping mechanism to tune out the current reality. To experience this for yourself, focus on a tense part of your body and close your eyes. Feel the discomfort and really focus on this for a moment. Now think of a happy memory, remembering the excitement, the joy. After a minute re-focus on the previous discomfort. Has anything changed? Are you less tense than you were? Consider leading an older person back to a happy memory, to lift their attention out of pain into pleasure. The mind used positively is an incredible friend.

⁴ Amanda Waring, What Do You See? DVD training pack (self-published), 2009.

Remember:

When confronting the pain of a difficult life crisis, carers may tell a person with dementia that 'everything will be fine', or not to be upset, sad or angry. Consistent negation of someone's emotional state can alienate them and make them feel as if their emotions are 'wrong'. Telling someone not to be upset can become a subtle form of bullying that needs to be avoided so that an older person does not withdraw, become resentful or feel invisible. Good practice in a carer recognises, values and validates the emotions of the person with dementia, while consistently communicating, 'I am here if you need me. I see your pain, and I will try and understand why you feel like this.'



Assess the following dementia-related dilemmas to encourage good practice.

Scenario 1

Mary, a resident in a care home, constantly accuses staff of stealing her wedding and engagement rings. She has arthritis and can't wear the rings. She does not want to put them in a safe, she wants to see them at all times.

What actions could be taken? How could she keep her possessions close to her and feel safe in her environment. Discuss.



- Carers need to avoid confrontation and to be aware of how Mary's behaviour could be related to, or mirror, deeper losses or previous experiences.
- Suggest to Mary that she could put her rings on a necklace, and wear them as a pendant, so care workers can show her where the rings are when she gets upset about losing them.
- Ensure that wastepaper bins are carefully checked over.

Scenario 2

George is a resident who often gets upset about seeing a figure at the end of his bed and hearing people talking in his room. What approach would you take?



 Hallucinations, can be fairly common, but avoid confronting George, or contradicting what he says he has seen or heard. Use a calm and comforting voice to reassure him and try and distract his attention to something real.

- Find out if medication could be the cause; seek appropriate advice.
- Be aware that dehydration can cause difficulties; check hydration charts.
- Ensure that checkups of eyesight and hearing are done often and that glasses and hearing aids are clean and working.

Scenario 3

Doreen an elderly resident wants to keep her independence but struggles with dressing herself. How can you help?

En Tip:

- Remember not to overwhelm someone with dementia with too much clutter or choice, which can cause further confusion.
- Consider using Velcro to replace buttons.
- Lay the clothes out in the order they are to be put on.
- Use labels, pictures and whole outfits together to simplify choices.
- Approach occupational therapists for daily living support.

Remember:

Dignity and choice means focusing on who the person with dementia is now, not on who they once were. In practice this can mean supporting someone in a different reality. The person may be wearing clothes differently, making food choices differently, occupying themselves differently, seeking new relationships differently from the way they have done these things the past. Trying to force a return to a past reality and using logic will not work if we are to be truly person-centred in our approach. Families who see it as their role to maintain a person's past wishes can strongly resist the practices of person-centred care, so skilful negotiation and communication to facilitate working in partnership with families may be required. The input of relatives is important, so it is vital to reach a clearly defined consensus.⁵



People living with dementia come to rely less on thinking and more on feeling. Providing emotional care is therefore vital and requires giving of yourself emotionally to support those in your care. When staff are working in this way, they need to be supported themselves through both informal and formal measures, such as:

⁵ Amanda Waring, *Heart of Care*, Souvenir Press, 2012.

- Daily debriefing
- Opportunities to reflect at the end of a day's caring
- Reflective supervision
- Group support sessions
- Learning opportunities to explore emotions at work
- External counselling sessions



Being emotionally engaged can leave you feeling drained, exhausted and empty, so it is important that you find ways to recharge your batteries and to keep inspired to keep on keeping on. The next step gives hints and tips on how to do this.

Step four: Addressing burnout



To provide self-assessment tools to help us recognise burnout, and positive ways to restore balance, energy and purpose.

Do not underestimate the emotional and physical toll that caring for others can have on us. When we neglect our own self-care, we can become burnt-out, physically exhausted and depressed. Even worse, when we are tired and burnt out, 'thoughtless' behaviours can then escalate into abuse, whether physical, or emotional.

Discuss:

Carefully consider these signs and symptoms of care-giver stress and how they may affect you personally:

- Regularly waking up tired in the morning and struggling to get to work
- Feeling that you are working harder but accomplishing less
- Becoming frustrated or irritated easily
- Losing compassion for some people and becoming over-involved with others
- Experiencing frequent illness, aches and pains

Exercise:

Working in pairs assess your compassion fatigue levels on a scale between strongly agree via neutral to strongly disagree, and then determine and take supportive action in respect of any statements you answered any degree of 'agree' to.

- I feel overwhelmed by the needs of others around me.
- I have felt detached from other people, I feel numb.
- I have bouts of depression and sadness and I have lost interest in things I used to enjoy.
- There are times it appears my work has hardened me to other people.
- There's a change in my humour: it has become darker, more cynical and sarcastic.



- I isolate myself and avoid people.
- I have an exaggerated sense of responsibility, and feel overwhelmed by all the things I feel only I can do.
- I am using alcohol or other substances more.
- I am enjoying work less.
- My attitude has become aggressive
- I have intrusive thoughts of someone's suffering
- I can't switch off or relax easily.



Consider making a personal pledge to care for yourself better, promising that from now on you will... Include elements from the Checklist to create a better balance.:

- Protect your time.
- Balance caseloads time and tasks.
- Set and maintain appropriate boundaries.
- Attend to your physical and emotional health.
- Make time for personal life.

- Feel grateful for three things each day.
- Reach out to the people you love.
- Find ways to acknowledge loss and grief.
- Allow yourself to cry.
- Putting things that you value, family hobbies, passions in your schedule.
- Have quiet time alone to relax.
- Be out in nature.

Discuss:

- What further ways can you support and nurture yourself? To give nurture means being nurtured.
- How can you place yourself at the heart of your own care?
- What support network can you find, whether professional or personal, to keep an eye on your own wellbeing?

Remember:

You are as important as those you care for.

Don't suffer alone or see your vulnerability as a weakness, It is merely a stage that you can and will move through in time – but you need not do this alone, so connect with your community, and make relationships with friends and family a priority.

Care for yourself emotionally, physically and spiritually so that there can be something left to give others!



Reflection can strengthen self-esteem, as we learn from our mistakes, observing our feelings and building on positive experiences. Keeping a diary is a good way to reflect on our experiences. Reflect on what you enjoy most about caring for others and keep this in your heart to help sustain morale. Refocus on the rewards of your work.

En Tip:

Keep hydrated! Dehydration causes tiredness, listlessness, irritation which can lead to thoughtless behaviour. Ensure that water is readily available.



Night-time carers

Being a night-time carer can adversely affect wellbeing. Inadequate sleep suppresses the immune system, making one more susceptible to viruses.

Here is a CHECKLIST to help you adjust and keep healthy from www.myhomelife.org.uk

- Organise your sleep time well during the day, making sure friends and family help you get the sleep you need.
- Eat healthy food at regular times.
- Drink more water, limit caffeine.
- Wear loose clothes and shoes.
- Have regular health checks.
- Do gentle exercise.

Exercise:

Often, we are giving more care than we are receiving. Draw up comparison columns of the care you give at work and at home, including feeding the fish, and so on, and what care you receive – someone making you a cup of tea, driving you, hugging you. If your sheets are unbalanced, ask for support from others to help. Give others the opportunity to help us, reach out and you may be surprised at what support there may be.



Guilt can play a terrible part in disturbing our wellbeing, if we have slipped up, we have another day to get things right and, rather than feel guilty, affirm that we will take the action that we can when we can. Feeling guilty can be a self-defeating habit, know that you deserve time to rest, to recharge your batteries.

Remember:

You are not meant to carry other's burdens for them at the expense of your own wellbeing. At the end of the working day find ways to disconnect from work.



Often, after a day of caring, one can feel exhausted, not so much from the physical labour involved in caring for older people as from working in an environment that can be emotionally draining. This can tire most people if little is done to lighten the atmosphere.

Having attachments and concerns regarding the people we care for is understandable, but it is important for carers to be able to disengage in their own homes, or wherever they may be in their own time, and to enjoy restful and restorative sleep.

Step five: Growing a culture of care



To provide ways to assess and improve the leadership of a culture of care.

In care, inspired and motivated leadership is needed more than ever to overcome the difficulties of budgetary constraints, staff retention and meeting targets. Good practice, like bad practice, can spread through a care setting, so ensure that your knowledge of person-centred care and dignity can be a guiding light to follow and learn from. Once a code of behaviour is acknowledged as best practice, as long as you, the manager or leader, up-hold and enforce it, it becomes much easier to gently remind staff when dignity and care standards are not being met.

Remember:

If managers do not treat staff with respect and dignity, that failure may be reflected in undignified interactions between carers and residents. Often there can be too much focus on targets and budgets, while the needs of older people and their families, and staff concerns, are lost from sight.





Exercise:

Leadership is needed that grows and develops its staff, nurturing both their relationships with older people and their caring skills. With a colleague whom you respect and trust to give you an honest opinion, share and reflect on your respective answers to the following questions, to see where you could improve. Develop action plans for yourselves, to reflect what you could do better, and the positive outcomes this could bring.

- Do I have good communication skills?
- Am I open to ideas, wherever they come from?
- Do I have a strong vision for improving care?
- Am I good at building effective teams?
- Do I make things happen?
- Do I respond well to staff concerns?
- Do I show appreciation easily?
- Do I listen well?
- Do I delegate well?
- Do I enjoy my work?
- Do I share positive news?

- Do I see both perspectives?
- Do I know the skills people wish to develop?
- Am I enthusiastic?



Your staff are on the front line and can provide you with fresh ideas and insights to improve the care of residents:

- How often do you ask them to contribute solutions and ideas?
- How well do staff feel supported by you?
- Are you more on the side of the residents and relatives than of the staff? Ideally, staff, residents and relatives need to be listened to equally, to ensure fair and considered outcomes.



Consider hearing the needs of staff first, at the beginning of a staff meeting.

At our staff meeting we end up listening to the manager who gives us a lecture for 45 minutes and then never gives us time to share our concerns or ideas. I am thinking of quitting because I feel demoralized by not having an opportunity to contribute — *Senior carer, Alton*

Remember:

Hopefully, your care home has a zero tolerance policy on all forms of abuse directed at residents, but how well do you deal with abuse directed at your staff? Staff often have to deal with residents with challenging behaviours, and they may, as a result, be frequently punched, hit and scratched, or they may have racist or sexist language directed at them.

🔁 Discuss:

- What agreed strategies have you in place to support staff in coping with or responding to such situations, and to strengthen their resilience?
- How well do you show staff that their wellbeing matters to you?



Managers could arrange to display a poster with photos of the staff, saying:

'Our staff have the right to be respected at all time. Thank you for being one of them.'

Remember:

- Very often night time staff are not included in staff meetings, so they can easily become the 'invisible carers', where pictures of all other staff are visible, but none of them are shown. Relatives often send thank you cards naming day staff but not night-time carers.
- Ensure that night-time staff feel as valued as every other member of staff, and ideally ensure that all day-time staff have done a night and all night-time staff have done a day, to foster mutual respect and understanding of each other's roles.

I got in for my night shift and Mrs A was wandering and restless all night. I finally got her settled and calmed by 4 am and didn't wash her that morning because I knew she was better off to sleep after such a disturbed night. But the first thing the morning staff shouted at me was , 'Why on earth have you not washed Mrs Aga? What do you do all night? Read a bloody book?'

I didn't get an opportunity to say my side of the story.

— Nina , night time carer.

It had been a hard shift, and Mrs T was very upset. She didn't want to get into her nightdress, she didn't want to get ready for bed, and so, in order to be person-centred I left her as she was. But the first thing the night-time staff did was bawl me out for not having got her into her nightclothes. They made me feel really bad and didn't want to listen to me.

— Jackie, day carer.

Consider:

A manager who is locked away in their office can often alienate staff.

Consider:

- How often you are seen 'on the floor'? A manager who is locked away in their office can often alienate staff.
- How well do you know the residents and relatives?

Our manager, she does not know the residents at all, she doesn't get involved, and if

she sees a towel lying on the floor in a corridor she will walk half a mile round the building to tell someone to pick it up and to criticize staff. Why couldn't she have picked it up herself and then assessed how it lay there? Maybe it was knocked off a trolley by a resident. She didn't offer a solution, she just snapped. — *Beatta, carer.*

Exercise:

Use the list below to make any adjustments necessary to improve the experience of the residents of your community, and to make your care setting a flourishing, person-centred place of growth and learning.

Which of the following is yours?

An institutionalised care setting:

- The setting is sterile.
- There is little social interaction. There are few activities.
- There is no involvement with the wider community.
- There is little access to the outdoors.
- Residents feel isolated and disengaged, with little independence or confidence.

A make-do care setting

- Activities have a one-size-fits-all mentality, with little choice or allowance for capabilities.
- Residents feel helpless and passive.
- There is some outdoor access, but only a small amount of contact with the community.
- No new learning opportunities are provided.
- Activity trainers have had little training themselves, and are not seen as vital.

A thriving care setting

- Activities are personal, relevant and inclusive of those with dementia.
- Activities are planned, spontaneous and developing.
- Enthusiastic management is seen as pivotal to the development of the home.
- There is easy access to the outdoors and good contact with the community, with the right balance between freedom and safety.
- Relatives, residents and staff are all involved in decision making.⁶

⁶ Based on David Sheard: *Enabling*; Feelings Matters Most series. Alzheimer's Society, 2007.



When you are a manager, or leader 'at the top of the tree', you may receive more complaints than thanks in any working day. It is important that you assess your levels of stress and burnout and seek support when you need it. Showing humanity and vulnerability as a leader in care can often help soften any sense of a 'them and us' division between staff and management, permitting better team building and joint empathy. But recognise the point at which feeling overwhelmed interferes with your ability to do your best. You deserve a life outside of care, so make sure you can switch off enough to enable your home life to be as unaffected as possible.

Step Six: Promoting meaningful activity and relationships



To provide practical ideas that enable older people to receive more support in everyday activities that enhance enjoyment, learning and quality of life as central and integrated elements of care.

The social environment should reflect the importance of relationships throughout life, and the fact that older people need rich social interaction that fosters continuing personal growth.

Consider:

An older person who is vulnerable or frail may have few expectations. If their self-belief and sense of identity is already diminished, it is likely they will withdraw, passively accepting the status quo. Exasperation, boredom and tiredness can be the consequence.



There is plenty of research to show how meaningful activity can improve physical and mental health. It is important to get a balance between giving the right level of support and 'taking over'.



Living means more than merely existing.

It means actively thriving and flourishing, to the extent that an individual can do so. Activities provide opportunities to reduce restlessness and agitation as well as for verbal and non-verbal communication. Activities have health benefits, raising one's mood, improving socialisation, and reducing dependency.

Use the checklist below to help you consider how you might help those in your care to engage in activities they might enjoy.

- What type of personality do they have: outgoing, shy ...?
- What kind of roles have they enjoyed in their lives? How can they be encouraged to maintain a role in ways that are important to them in their current community?
- What have they enjoyed in the past?
- What might they like to do to provide a sense of continuity with the past, engagement in the present and consideration of the future?
- What levels of assistance do they need to follow through an activity?
- What attention span do they have for sustaining interest and concentration?
- Do they like company, and if so how much?
- Do they prefer to spend time alone?
- Are they a morning or an evening person? When does their energy dip? Tailor activities to fit with their timeframes and energy levels.



Exercise:

Can you discover a variety of activities and interests that can:

- be fun
- be energising, energetic
- be peaceful, gentle
- be done alone
- involve a mental challenge
- engage the senses
- be experienced as something completely new?

Remember:

- Activities should be directed at improving well-being.
- The ability of a person with dementia to engage in an activity will decline with the progress of the disease. It is therefore important to regularly review which activities the person responds best to.
- Matching a task to a person's skills and abilities will ensure that the activity is not so
 easy as to become boring, or so demanding as to become stressful.

Entry Tip:

- Encourage relatives to bring in photographs showing important places, holidays, events and interests with explanatory notes and captions, so you can be inspired to 'time travel' with your resident.
- Memory boxes are a useful tool. For example, a memory box for someone who likes gardening could include objects such as seed packets, gardening gloves, fir cones, herbs, fragrant floral sachets, recordings of birdsong, and pictures of flowers and trees. Get creative. Develop memory boxes for group interests as well as for one-to-one sessions.

Consider:

Although some people may benefit from being connected with a former interest, others may not. Their abilities and preferences may have changed or it may be too painful to be reminded of an activity that they used to enjoy with friends and family but can no longer take part in. A sensitive approach is required, so never force or bully someone into participating in an activity.



Discuss:

Having purpose, a sense of achievement, and a sense of being needed is necessary for people to continue to thrive spiritually. Focusing on purely medical needs may leave emotional needs for purpose and fulfilment untended.

How many ways can you provide opportunities for older people to contribute or to 'give care' to others? Examples might include folding clothes, arranging flowers, laying the table, reading to others, singing, and so on.

Consider:

The following scenario:

I can't get used to not being busy anymore, or wanted. In my road I was always the one people would come to first for baby sitting, dog walking, cake sales and such. I just don't see the point of me anymore. I knew everyone on my street, I don't know anyone here. I am tired all the time and I can't bear it when the morning staff are so noisy; they wake me up every time they arrive

- Mrs Jameson, (83, care home resident)

It was gently suggested that Mrs Jameson set her alarm and get up before the morning staff arrive, in order to welcome them in like a commissionaire. She was initially a little suspicious, but she tried it and loved it. She had found a role – a purpose. Staff really

appreciated being welcomed to work in this way and Mrs Jameson felt that she had a responsibility to welcome them into 'her home'.

This also reminded staff that the care home was her home and the home of the other residents, something that can easily get forgotten in the busyness of care. Mrs Jameson got to know the members of staff, and they her, and despite the early start her energy levels improved!



Think of ways to bring people together, creating a sense of community and making use of all the skills, talents and interests of all members of staff and residents.

Step Seven: Spiritual and emotional care



To ensure that older people's spiritual needs are identified and valued as integral elements of their quality of life.

Spiritual care is a fundamental part of nursing currently much neglected through ignorance and misunderstanding.

- Royal College of Nursing.

Spirituality can be used to inform and help an older person to facilitate healing or recovery. Loneliness, boredom and a sense of helplessness can overwhelm the human spirit, especially in people who are frail, or who suffer enduring pain or chronic illnesses.



In old age, whatever our faith, or lack of it, the human need to put things in order, to forgive, to be listened to, to feel safe, and to find peace, acceptance, hope and understanding becomes especially important.

The importance of understanding how to support the spiritual needs of those in your care cannot be underestimated. Good spiritual care is as important as good medical practice. Therefore provision must be made for spiritual needs to be met where possible, and included in care settings.



Spiritual care is not solely about religious beliefs and practices. It is not a specialist activity or the sole responsibility of the chaplain, rabbi, imam or other religious professional. It is about being open enough to meet people at their deepest needs.

NHS Education Scotland defines spiritual care as:.

... that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness [...which] can include the need for meaning, for self-worth, to express oneself, for faith support for prayer or sacrament or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction needs requires.



Active listening is a powerful tool for supporting the needs of others. Having regrets, losses, unresolved difficulties or troubled relationships can be a natural source of stress. Some older people may want to reflect on such circumstances, and perhaps share their thoughts and feelings with others who can help by listening, without necessarily trying to fix anything or change the situation, but by just receiving the words of the older person, who may then be able to relieve the cause of tension in their own mind or to accept it.

Exercise:

Experience active listening.

In pairs, take turns to share a powerful and meaningful memory. The person that is listening must not interrupt, but only listen, and then repeat back to their partner the memory they shared.

- People are often anxious about this, but when you listen from the heart you will be amazed how much more you will remember and have empathy for the speaker.
- It is surprisingly easy for us appear to be listening while our mind actually wanders, but once the carer learns how to listen actively and attentively, each participant will feel validated and able to reach a clearer perspective on their own memory too.

Emotional and spiritual care is a two-way process that allows older people to share with and minister to us too, through their words and insights. This is humbling for us and enlivening for them. Offering older people the opportunity to provide emotional support, and to give as well as receive, is a powerful restorative tonic for the soul.



It is never right to impose your own beliefs and values on anyone, nor to try and convert anyone to your own faith.

Consider:

As people age, they may feel a growing need to share, to express themselves and hand down what they have learnt through the years. Provide opportunities for this sharing, and acknowledge older people's value by giving them a diary to write in, videoing them or making voice recordings. What other ways could you suggest?

Discuss:

Discuss what values you live by and why?

It is important to identify your values, as they determine what you bring to your work environment, and form the basis of your actions with the older people you support.

- To help you identify your values, consider the list below to see which words most resonate with you.
- Acceptance, appreciation, balance, benevolence, clarity, centredness, commitment, compassion, cooperation, courage, dependability, dignity, enthusiasm, forgiveness, flexibility, generosity, gratitude, honesty, hope, humour, inspiration, integrity, kindness, love, loyalty, openness, patience, peace, practicality, respect, responsibility, tolerance, trust, wisdom.

Consider:

Trying to discover the values of those you care for, as they reveal so much about a
person. During times of crisis and stress we can help remind one another to remain
true to our values.

Address regrets.

One of the most important things you can do as a carer for those near the end of life is to provide opportunities for the mending of broken or troubled relationships. Regrets over what one might have done, could have done, or should have done may surface quite dramatically in older people when they are faced with a life threatening illness. Gentle, empathetic and emotionally supportive skills are needed to guide them through any mire of self-recrimination, guilt or loss.



Discuss what regrets you may have at your moment of passing.

Allow members of the group to share their thoughts honestly in a safe, non-judgmental space. Then ask them to explore how this exercise can help them connect with and understand the residents they care for.

Consider:

When we ask carers what they do when they are stressed, or have had a bad day, or how they make themselves feel better, their answers include phoning a friend, going shopping, walking the dog, taking a hot bath, enjoying a glass of wine, playing with my children, hugging a spouse or partner, running, getting a massage ...

We then ask them to consider whether they have discovered what used to make the people in their care feel better in 'the outside world', and what freedom they now have to do any of the same things?

Use the CHECKLIST to inspire you:

- What piece of music lifts their spirit and can this be made accessible on a handheld device, so can you listen to it and appreciate it together?
- What is their favourite scent, or uplifting smell: lavender, honeysuckle? Could you bring a fragrant pillow or spray to help them when they feel down? Small personal things make a big difference.
- If they used to enjoy walking in nature, can you bring in a few pine-cones for them to hold, or some of their favourite flowers?
- What TV programme or comedy used to make them laugh? Can you access copies?

- If their spouse or partner can't be with them, can you arrange for a greeting from them to be sent and played often on a handheld device, or for 'Facetime' moments, to complement encouraging visits?
- If an older person used to like to walk by the sea when they were unhappy, can you bring in a bowl of sand that they can run their hands in , or some shells, or a CD with the sounds of the sea?
- Think of any other ways that may help.

Put your findings from the above exercise into the care plan.



Create an emotional care trunk.

When residents are unhappy and experiencing emotional pain or distress, a good way to help support them, and to assist staff and relatives in reaching out to them, is to have an easily accessible emotional care trunk. There should be one on every floor of every unit.

This is a box or trunk containing an assortment of things to help the wellbeing of a distressed resident. Include things from the checklist below, but personalise and add any other things you feel would provide comfort and solace.

- Soothing hand lotion, for hand massages
- A CD player with a collection of relaxing music, sound of the sea, birdsong, etc.
- A warm, super soft blanket
- A collection of different fragrances
- Strokeable material such as velvet soothing to hold
- Uplifting colouring books and pens
- A collection of inspiring, uplifting poetry
- Humorous verse
- A Bible, a Koran, or other religious or philosophical books
- Comedy audio recordings
- A weighted blanket

Consider:

Weighted blankets, wraps or lap pads are often used to alleviate distress with people who have autism, but they also work exceptionally well in dementia care. A weighted blanket or jacket, is a safe and effective therapeutic aid, calming the body and also conducive to a peaceful night's sleep. Deep pressure touch, almost like a firm hug, helps the body relax, enabling the person to feel secure, grounded and safe. Weighted blankets can also help calm restless legs and many other symptoms experienced by people who are agitated, including patients with Alzheimer's and Parkinson's disease.

Consider making your own such blanket as a joint project within the care home, as a productive and constructive activity – there are instructions on Youtube. Otherwise, they are easy to purchase.

P Discuss:

To enhance emotional wellbeing, in what ways could you provide more opportunities for older people to:

- enjoy creativity, and continue learning
- rejoice in remaining skills and be thankful for them
- experience a sense of continuity in life
- keep and develop a sense of humour
- feel listened to
- maintain dignity and respect
- have a sense of peace
- love and be loved.

Tip:

Here are some ways to help support these needs:

- Encourage and enable older people to enjoy life by using their existing abilities.
- Encourage the sharing of feelings, hopes and fears.
- Support the inner values and beliefs that help people cope.
- Through building relationships, learn to know the older people well enough to provide a varied and interesting day.

- Recognising the themes, symbols, religious cultures and philosophies that are important to people in your care.
- Know your own strengths and limitations.
- Pay attention to your own emotional and spiritual needs; if you feel out of your depth, seek help from someone you trust, or contact interfaith ministers or other support networks.
- Be aware when it is appropriate to refer to another source of support such as chaplain, counsellor, family member or friend.



How do any of the spiritual and emotional needs of older people differ from your own needs?

Follow-up to this guidance

If you would like to explore further any of the themes touched on in *Doing It Well*, we can send you more information or can arrange to speak directly with you or your team about our work and our approach. We also have a number of trainers and coaches who we can put you in touch with if you want to develop further work in this area. Finally, we have a number of relevant videos and materials available for purchase.

For further information, please contact Angela Tunnicliffe: angela.tunnicliffe@bjf.org.uk Tel: 01782 844036

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