



Honoured Guests

Welcoming, involving and supporting the families and friends of people who are living in residential care

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Introduction

"I quite like the title 'Honoured Guests'," commented Professor Martin Green. "It reminds people, whether we are family or friends, that we are there as guests of the resident. This title also reinforces that staff and relatives should have one purpose, which is to support the older person who is resident in the care home – and that their contribution is well-regarded."

This is a fundamentally important insight. Good staff in care homes are used to reminding one another that "the residents don't live in 'our' home: we work in theirs". By positioning the care home resident as the "host" – the person who would have issued the invitation or requested the service, had they the agency to do so – both staff and visitors maintain that person's dignity.

The host / guest relationship is one that is understood through all cultures.

If the care home manager thinks themselves into the role of facilitator – the Housekeeper of a mansion, perhaps – they may find that many of the conventions of hospitality; greeting with courtesy, ensuring comfort, arranging facilities, anticipating requirements, managing departure graciously, will help them achieve success for individual hosts and guests and for their community as a whole.

Many of these functions can also, now, be managed virtually for the benefit of those people who the resident would have wished to invite but who live too far away to visit in person. Younger staff members working in care homes have levels of technological expertise that can be used to reach out to residents' family and friends whether they may be in the world. The currently cosmopolitan mix of staff may be an untapped source of strength in this respect as many foreign-born workers have personal experience keeping in touch with families abroad.

Comfort and comforting

The need for relationship repair?

The Housekeeper (or care home manager) arranges for residents and their guests to be made comfortable but they may also need to be comforted. The day someone relinquishes the independent living status that is the norm for adults in our society (however much that 'independence' may have depended on the efforts of others) is a watershed day: "I'm sorry I just can't cope anymore." Whether that's said by the person making the move out from the domestic setting or the person who has instigated that move, it is likely to be felt as a defeat. If the move has been imposed by external authority who will not "allow" a return home from hospital there may also be resentment, particularly if that home must now be mortgaged or sold to pay for the unchosen care.

It is illness, disability, increasing frailty that has forced the change, not the actions of others. Nevertheless it may feel personal. Emotions around this time of transition may include anger, abandonment, rejection, uselessness, personal failure, grief, anxiety, guilt. Such negative feelings are likely to persist if relationships with family and friends cannot be integrated into the older person's new life. The watershed moment of moving forces people to confront their separateness: must they necessarily become inessential to one another?

We are not used to thinking of ourselves as the "guests" of people we love but there is a sense in which we were,

long ago, invited into their lives. We accepted that invitation and issued our own in return. The physical separation, when a spouse, life-partner or parent moves into residential accommodation, may feel like a premature bereavement but it need not. A care home manager or other professional who is able to help residents and their families and friends maintain (or renegotiate) their relationships through the watershed is nurturing something that is of crucial importance. For people to live well they need more than material care, they need to be emotionally comfortable with themselves and with the others around them. Honoured Guests believes that supporting residents' pre-existing relationships is an essential aspect of care.



The wider benefits of relationship support

The Care Quality Commission has recently published revised **Key Lines of Enquiry, Prompts and Value Characteristics in Adult Social Care**¹ which are intended to come into action later in the year. They place noticeably greater emphasis on family and community involvement, including the involvement of those who live far away. Integrating the people who matter most to residents has the potential to enhance all the CQC Fundamental Standards of care including staffing and governance. Many of the ideas and insights in Honoured Guests have been contributed by care home managers who are part of John's Campaign, a UK-wide movement that advocates for the carers of people with dementia. We hope that sharing these examples of existing good practice will inspire other providers to find their own routes towards excellence. Every residential home is an individual entity and all the people within it have their own unique and complex network of relationships.

Welcoming, involving and supporting the families and friends of residents is a viable approach to the challenge of providing best care for the increasing number of people living with dementia and frailty in care and nursing homes. It is essential for end-of life care.

Honoured Guests is also a response to John's Campaign – a national movement which began in the acute hospital sector but which has relevance for all settings where people living with dementia or frailty receive professional care. John's Campaign advocates for family carers always to be welcomed and involved, for access to be unrestricted and for their special

contribution to be valued. It is perhaps closer to a movement than a campaign as there are no specific requirements, apart from adherence to the essential principle. Family members who are caring for others cannot (or should not) be dictated to: working with them means accepting what they chose (or are able) to offer. Management is by conversation, negotiation and encouragement.

John's Campaign extended into residential care when family carers, used to caring at home, then continuing to care in hospitals which had adopted the campaign principles, found themselves rebuffed by nursing or care homes. Other relatives complained that they were not welcome to share meals or drop in at times that suited them but conflicted with the institutional routine. It was additionally obvious that the free access of families and friends into residential homes is an indicator of openness and therefore a safeguard against abuse. At the time of writing approximately six hundred homes are signed up to the campaign and are developing an active relationship with the people who matter most to their residents. There is plenty of good practice to be shared.

Jane Montrose, owner of Apple House Care, outlines some characteristics of "Family Friendliness" - inclusion, partnership, approachability, homeliness, communication, and flexibility. These principles are equally applicable in homes for people with learning disabilities as well as those living with dementia or frailty. One of her homes, Summerwood, was recently rated outstanding by the CQC and praised for its involvement in John's Campaign.²

1 Welcoming residents' family and friends

Before arrival: paving the way

Welcome is a process that begins long before anyone makes their way to the care home front entrance. Time taken to send news and photos to community free sheets, parish magazines or local papers – or share to Facebook - is time well spent. It tells people that coming to live in residential care is not saying goodbye to the world. Participation in national initiatives like #carehomeopenday offers an annual opportunity to demolish any invisible Keep Out signs but there's much more that can be done, both locally and virtually, to build familiarity and ensure that any future move or visit will feel safe. This need not conflict with the need to protect the individual privacy of people living in their own home as long as guidelines are clear and appropriate permissions scrupulously obtained.

Suggestions:

- Set yourself (or staff as a whole) a target to provide regular items of good news. Share these internally, locally and electronically. If you're not confident using social media find someone who enjoys this method of communication and delegate to them.
- John's Campaign is a UK-wide movement – use signing up as a positive item of good news.
- Make sure communication guidelines are clear, agreed and

shared and that all permissions are updated as necessary. Encourage families and friends to take and share photos of themselves and their relative but make sure they too understand the importance of the permission procedure and respect for other people's privacy.

- Ensure that your marketing material reflects your ethos of welcome and partnership whilst always respecting individual preferences and choice.
- Have a stack of "Change of Address" cards that include your website, Facebook page, twitter handle (or whatever you have) as well as postal address and phone number. Offer these liberally to families when a new resident is moving in.

Managers at Guide Total Care are using their sign up to John's Campaign as part of an overall push to raise standards in their Chelmsford Care Home. When they pledged their welcome on Memory Day they invited relatives and professionals to a celebration lunch and discussion of best practice dementia care. They used banners to raise awareness and sent a letter to all families and staff explaining what this meant. They have included the letter in staff induction packs and are actively involving their main care agencies. ³

As guests arrive

Consider the physical experience of arrival and its role in creating an initial impression. Try looking at the entrance through the eyes of others – a visiting grandchild, for instance, or someone arriving in a wheelchair. Is it well-lit for people who arrive after dark? Is signage clear for people with poor eyesight or speakers of other languages? Are pets welcome?

What about the out-of-hours and weekend access arrangements? Residents want to know that their guests can visit freely but they also need to feel safe. Families and friends may expect to be able to pop in at any time to give Grandma a hug but they will be rightly disturbed if she is subjected to unwanted intrusion. People's habits vary as they receive visitors. In some households spontaneity may be the norm, in others all comings and goings will be pre-announced (except in dire emergency). There may be times of day when the resident prefers to be left alone or people he or she no longer wishes to see. It's an individual choice.

Do people feel welcome as soon as they arrive? Once again it's worth looking at this through other people's eyes – not just for the practical aids to accessibility but for the intangible creation of an atmosphere. Make sure there's plenty to interest visitors if they have to wait in the reception area - a family notice board or information box. This could include information about neighbourhood events as well as invitations to training courses, spare copies of items in the guest folder (see below), requests for feedback, causes for celebration – and a John's Campaign certificate(!). Replicate as much as possible on a website for people who are less able to visit in person.

A smile and a greeting is the best welcome of all. Make these universal and invariable. Names are vital – and so are staff name badges. It's a simple act of courtesy in an environment which may otherwise seem bewildering. The #hellomynameis campaign has showed its potential to transform relationships in hospital and it's no less relevant in



care homes. Residents with dementia especially will find names elusive and will feel diminished because of their inability to remember. Constant introductions and re-introductions help put them and their guests at ease. Agency staff should have name badges too – for their own sake, a name gives personhood.

Initially new arrivals and their guests may find some of the other residents alarming. What about residents who shout out, spit their food or take off their clothes unexpectedly? A good manners policy of individual acknowledgement for everyone will be reassuring. Don't ignore a resident who is behaving unconventionally but greet and introduce him. This simple courtesy confirms that he is not a scary stranger; he is someone else who is living in this place. A friend they haven't met yet.

Suggestions:

- Seek feedback on both the intangible and the tangible aspects of accessibility and the creation of a welcoming atmosphere.
- Establish systems that allow anytime entrance for those people most needed by your residents whilst preserving security for all. Keep communication of these arrangements up to date.
- Implement a whole staff policy of #hellomynameis. Ensure that agency workers know that this also includes them. Insist on the importance of greetings, introductions and polite farewells.
- Produce a “guest pack” of information. Keep adding to this and duplicate the contents on a notice board, information rack or website.
- Use our Quick Guide to give initial guidance to families and friends or develop a leaflet of your own.
- Ensure that people who are unlikely to be able to visit in person have equivalent virtual information and can “see” where their friend or relative lives. Offer a video tour that includes more than neatly arranged furniture and an empty garden.

The HC-One company produced a welcome leaflet for families to promote their involvement in the care of their relatives. They have also have instituted a system of name badges for all their staff that includes an item of personal information. These are proving very successful in promoting conversations at all levels.⁴



During their visit – facilities & activities

Residents and their guests should be asked how they like to spend their time together – as part of a general social group (in the lounge for instance) or privately (in the bedroom or in a quieter sitting room)?

Ensure that privacy is always possible. Which outdoor areas are most easily accessible? Is there anything that will make visiting more fun for children – a play area, adventure trail or a stack of board games? Tell visitors about meal time arrangements and ensure they know that their participation is welcome, even within a “protected mealtimes” policy. If there are facilities for guests to make additional drinks or snacks for themselves or the person they are visiting, explain how this is organised. If they are used to tempting their relative's appetite with little treats they have made or purchased themselves, discuss where these might be stored. Their time together is important and their preferences count. They need the confidence to transplant their established relationships to this new place.

Essential questions are: what have you been used to doing together? Which would you like to continue? How often do you normally see one another? How regularly do you hope to visit here? If someone is already living with dementia their capacity for re-orientation and the making of new relationships is likely to be limited. They need the people they know – and they need them as regularly as possible if they are not to lose those memories too in the bewilderment of their new surroundings.

It's important that families know that the care home staff are not their replacements, but their extension and practical support. Research has shown that the earlier a visiting pattern is established the more stable it is likely to be, though of course there will always be fluctuations and flexibilities.⁵ If staff members know that someone's son will usually be popping in a tea time on a Tuesday (because that's what he's always done) they can use that information reassuringly. Managing this level of detail may feel daunting but guests may be asked to help, perhaps by pencilling in a diary or calendar if they know when they're likely to come again or using a wipe-clean board in a resident's room.



Even in a small care home there will be a lot of information for families and friends to assimilate. Is there a guest room bookable by visitors who have travelled a long distance? Or a bedside bed for overnight stays in emergency or towards the end of life? How can Skype sessions be facilitated? What special events (like relatives meetings) should visitors put into diaries? Collect this information in "guest folders" so it's there when needed.

Managers may not be able to provide for all requirements but once families are engaged in an open discussion they may feel sufficiently confident come up with their own ways to personalise their visits. Be ready to say Yes.

Suggestions:

- Ask residents and their families and friends how they usually like to spend their time together and do your best to signpost or provide facilities to replicate this.
- Clarify eating arrangements – especially if you have a "protected mealtimes" policy. Make sure that guests know they are welcome.
- Collect information about available activities and facilities and share this in a physical format and via your website.
- Encourage your residents and their guests to use their own initiative and develop their own strategies to enable happy times together. Offer support for special family events.

The Abbeyfield Society is working with Dementia Adventure to make the most of their outdoor facilities for their residents' pleasure and also for the enjoyment of families and friends. ⁶



2 Involving residents' family and friends

Many guests will simply want to visit: spend social time together, check their friend seems okay and leave. But will they come again? The best way to keep people visiting is to let them know that they matter. Help them to feel involved, whether emotionally or practically. Their host may become progressively less able to play an active part in the social exchange but staff

members can highlight the non-verbal aspects of friendship. Thank visitors for encouraging their friend to drink an extra cup of tea; tell them how he's brightened up now they are there; remind them that it's illness not lack of appreciation that has disabled him from saying these things for himself. Most people like to know that they have made a difference.

Guests as “monitors”

Involving Families in Care Homes, an excellent publication from the Bradford Dementia Care series⁷, identified three main aspects of family involvement: “socio-emotional care”, advocacy and monitoring. The last is possibly the most daunting - the guest from hell who is always metaphorically running her finger along the back of the radiator in the hope of finding a speck of dust about which she can complain. Does involving family mean welcoming an army of amateur inspectors?

The answer of course is yes. Humans are inquisitive and anyone who comes to the door – even the postman – is likely to be taking a quick look round to see what it's really like. A crucial trust-building phase in the relationship with residents' guests comes immediately after admission. They are likely to be hyper-vigilant but also wary of creating any bad feeling by direct questioning or complaint. That won't stop them fretting, however.

The guest packs and website can contain instructions who to speak to if visitors are unclear or unhappy about anything they observe. Build in frequent and regular review opportunities during the first few months and try to keep an open office door. If there's been any safeguarding incident – a fall, an altercation with another resident - make sure your main family contact is told about it immediately and directly. Don't wait for them to find out about it from anyone else. There may be a moment of immediate unpleasantness but complete openness is the strongest reassurance for the long term.

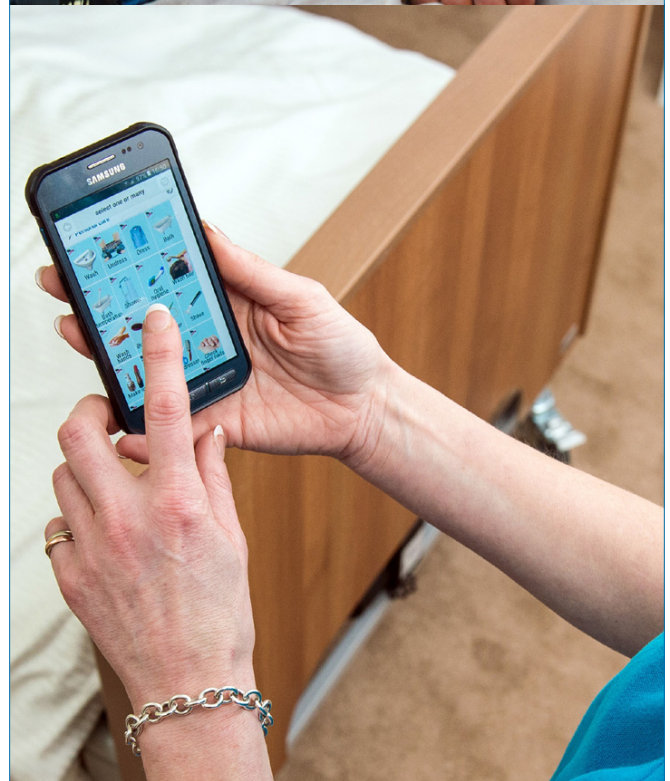
Other instances of amateur monitoring may feel more difficult – the level of complaint perhaps unreasonable – and relationships between guest and care staff may begin to sour. One of the most frequently cited reasons for people to stop visiting is poor relationships with staff. A manager's duty to the resident makes it imperative to intervene.

The family member may need support with some personal difficulty or the staff may need reminding to view the issues from his (or her) perspective. Perhaps expectations could have been better managed at the outset? Did the promotional material promise more than even superheroes could perform? Or is the complainer still privately guilt-ridden because he believes he should be caring for his wife?

Suggestions:

- Identify one or two key family members who must be contacted if there is a safeguarding incident or emergency. Never neglect to do this, even if there's been another visitor present.
- Consider what level of detailed information you can make available electronically to family members who want to keep an eye on things from afar.
- Ensure your initial marketing doesn't promise more than you can perform. Be honest and manage expectations realistically.
- Reassure relatives (and residents) that you are always willing to listen to their concerns and will take them seriously. Never avoid asking how things are going when you meet casually.
- Ensure relatives and residents possess all the information they need to express their concerns at any level (use your guest pack and website).
- When someone seems consistently dissatisfied be proactive in trying to find the reason why. It may be that their expectations are unachievable or that they need personal support. Or they might be right...

Christine Asbury, chief executive of WCS Care champions transparency in care and explains how their “Relative’s Gateway” system provides friends and relatives with a window into a loved one’s care notes in near real-time, wherever they are in the world that has an internet connection. Six of the thirteen WCS homes are currently rated outstanding by the CQC. ⁸



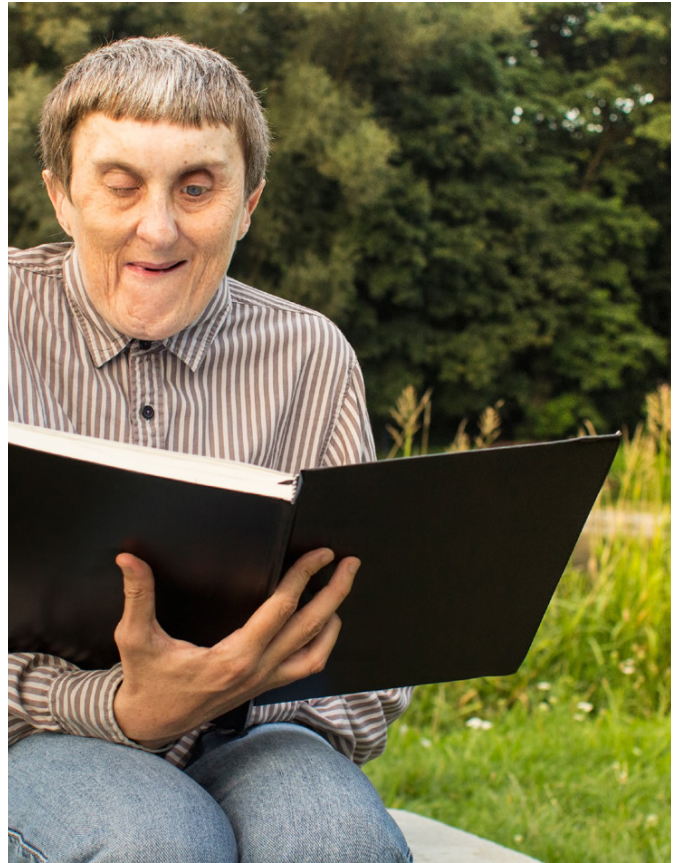
Guests as advocates

Involving families as advocates is not usually hard as it's likely that they will be acting in this capacity from the moment they make their first enquiries until after their relative's time in the care home has come to an end. They may have legal responsibilities but the extent to which they wish to be involved in day to day advocacy depends in part on their understanding of the new balance of responsibility. Does the lead family member or friend still see him or herself as primary carer or are they handing this role over? If, for instance, the resident needed to go to hospital in an emergency would there be a family member available to accompany and speak for them?

Ideally advocacy will be shared, pooling personal and professional perspectives. However, it's perhaps in this area of their involvement that caution about preserving the structure of relationship is most useful. Staff and family members working together will provide a firm foundation for the triangle of care but it may be too easy to disregard the person at the top and fall into the discourteous habit of talking across the resident, or speaking at a pace or at a level of complexity where they cannot follow for themselves. Thus, inadvertently making them feel excluded where they are most concerned.

Complex conversations are frequently essential but it's an aspect of care that needs to be managed with correctness and sensitivity, never forgetting the essential issues of consent. People do not freeze-frame because they have moved into professional care – in fact this may precipitate change. As Rebecca Bewley writes, *"People with dementia must have the freedom to*

*change their preferences – someone who has never taken sugar in her tea may develop the sweet tooth of childhood and a previously demure person may start to choose bright red nail polish."*⁹



Helping people to find their voice and express their continuing identity

Perhaps it should be obvious but visitors may not always realise the extent to which they are practising advocacy on every single visit as their special relationship helps their host find his or her voice. It may be that residents grumble more and seem less settled when they are with their guests and it's probably helpful to acknowledge this difference in perspective from the outset (and welcome it).

Life Story work is an immediate, most valuable and obvious way to involve residents and their families from before the moment of transition to the obituaries and beyond. Life story work is a potentially a **process** as well as product - an activity for every visit once it is accepted that living continues every day. Nevertheless life story information should also be requested as a **product** – a short cut to getting to know a person who may not be able to communicate easily for themselves.

When this request is made at the beginning of a new relationship, families (and the resident) need to be told how this information will be shared – is it an open access, quick reference summary to assist any member of staff (an agency worker perhaps) or is it of a more intimate nature to inform detailed care-planning and medical history.

A life story book (or photo album or timeline or music playlist or DVD) may also be compiled for the direct use of the resident themselves, to

support their own memories and sense of identity. Being clear with family members about the intended use for their information should help them make appropriate decisions about what aspects their relative would have authorised them to share, had they been able.

Suggestions:

- Make full use of family and friends as advocates – whilst remaining sensitive to the likely wishes of the person on whose behalf they are speaking.
- Address the issue of people speaking differently to different audiences and accept that residents may seem more “unsettled” when in the company of their guests.
- Be wary of inadvertently excluding the person's own voice or failing to check for consent.
- Remind yourself and the relatives that people can continue to change and preferences need not be set in stone.
- Help people to continue to tell their own life stories but when it's necessary to ask others to provide biographical information or medical history be sure they know how it will be shared and used. Chose an appropriate format to support this.

Care staff at Retirement Villages The Moat House in Essex, pupils at Saxmundham Free School in Suffolk and participants in the NOT Forgotten Lives project in Felixstowe have put their ideas together to create a new type of Life Story booklet entitled Please Tell Me.¹⁰

Family and friends as caregivers

Monitoring is important and so is advocacy, but the day by day or week by week involvement of families and friends in “socio-emotional care” (or what one might call cherishing) is arguably the aspect that has greatest potential for good. The conversations that take place around the time that the person is preparing to move into his or her new accommodation set the tone for the future relationship between the staff who are to be paid for the daily care and those who are personally essential to their well-being and who may previously have been managing the daily care as well.

Perhaps there are families who are so near breaking point that they intend to dump their relative and vamoose but for most people what is needed is a re-negotiation of roles. Their status in that person's life is unchanged: they are still sons, brothers, next door neighbours for over fifty years. They still assume and want involvement but they are not necessarily sure how it should be expressed in the new circumstances.

It may be that their uncertainty is part of a larger social ambivalence about the balance between public and private responsibility. Currently the situation is polarised. Either families look after their older relatives by themselves at home, usually with a breaking-strain burden falling on a single person (cf Carers UK research¹¹), or their relative moves into a Care Home and they feel they have become redundant. Open-minded conversations at the time of transition will help individuals and perhaps the wider interest in the John's Campaign partnership approach shows we are entering a time of change.

Avnish Goyal, managing director of Hallmark Care Homes has launched their new dementia strategy “Together” focussing on relationship-based care. Outcome 10 focusses on wide-ranging and achievable strategies for making partnership work and family support a reality.¹²



Early conversations

However routine the procedures of assessment and admission are to the care home manager, to the family all this is likely to be new. If the main focus of the discussion is on the resident's emotional and personal needs (rather than their likelihood of "compliance" in the shower) family carers will swiftly be reassured and begin to realise why they are still essential. They know what is "normal" for that individual – and someone who is living with dementia usually has an unquenchable longing for what is "normal". Normal is reassuring (though increasingly unattainable) but normal varies wildly from person to person.

This is well-understood on the practical level – tea or coffee, bath or shower, food chopped-up or pureed? Person-centeredness will prompt more important enquiries about the individual – gregarious or solitary, active or sedentary, early riser or night-owl? The key questions for family and friends, however, are those that tease out the norms of relationship: how are you usually involved in this person's life, what have you been doing with and for them, which aspects would you like to retain and which would you like us to take on?

These must be open questions without any assumptions, particularly in the area of personal care: one exhausted wife may never want to change her husband's pads or clip his toenails again. She may long for time to restore and rediscover herself and then, perhaps, the opportunity to recapture something of the intangible and joyful in their relationship: another woman may be deeply distressed by the thought of strangers performing such an intimate function. This is their choice, there is no right or wrong. And the saving grace of good residential care is that there is a genuine choice.

Adam Purnell, domiciliary manager at Kepplegate Care Services has re-organised their website to reach out to family carers in support of John's Campaign. Kepplegate offers accommodation for family carers at all times of need, including the first nights.

Their website explicitly challenges the "taboo" areas of family carers remaining involved with personal care. ¹³



Suggestions:

- Use the early conversations around admission time to ask what is “normal” in the caring relationship and which aspects might be carried over into the new setting.
- Be honest about pleasures which you will or will not be able to facilitate. For instance if the new resident enjoys a long walk every day you may not be able to spare a member of staff and will be glad of family input.
- Explicitly ask whether there are aspects of personal care that they would like to continue (or that their relative would find particularly distressing if performed by a stranger). Let them lead the conversation at this point. The only right answer is the one that suits both the people involved and enhances their relationship.
- Recognise that people may have developed their own routines for personal care which don't necessarily conform to the approved pattern. Discuss this respectfully. If you think there may be a Health & Safety / insurance issue consider a disclaimer.
- If relatives are likely to have a significant amount of direct input into care – regularly making and offering drinks for instance – you might consider whether this needs to be included in your record sheets. Families are likely to be glad to co-operate.



Managing regular departures

One of the most difficult moments of a successful visit is when it has to come to an end. This can be so distressing for both guest and host that it may even deter future visits.

To some extent this may be unavoidable: no matter how good and person centred the care and facilities may be, some residents will always have a deep longing to go "home". The word home, especially in the case of someone living with dementia or anxiety has a powerful emotional charge, similar to "normal", possibly representing a lost state of mind and unattainable way of life as much as a physical place. Saying goodbye to guests who announce they are "going home" may evoke longing and accusations of abandonment in the resident; feelings of guilt, distress or frustration in the departing guest. They may even worry that they have "unsettled" their friend or relative and perhaps should not come again.

It may therefore be worth giving a little thought to the language used: "This is where you're living now" is perhaps a more diplomatic phrase than "this is your Home". Departing relatives might be encouraged to announce that they are going to "my office" or "my place", "back to my house" rather than "home". Choosing the right language may be a way of subtly underscoring the new host / guest relationship – we are not a mother and daughter torn asunder: we are two people who have an enduring relationship but who live at different addresses – as adults often do.

Immediate reassurance re return is obviously helpful and the more specific

the language used the more effective it may be. Even when people are disorientated in their understanding of time, "tomorrow" sounds better than "soon" and "Friday week" will be more definitely encouraging than "some time". Ideally there will be some means of recording when the next visit is planned, a diary, calendar, wipe-off board?

Some guests may be tempted to slip away without saying goodbye. This is not a way that we normally treat other adults. It's likely to leave the resident more confused and, if it's a regular occurrence, it may prevent them from feeling completely relaxed and confident during the visit. If visitors remember their "guest" status and thank their "host" for "a lovely time" that at least preserves some self-esteem in the resident even if there is a moment of natural sadness. Ideally the guests should be able to tell a staff member when they are leaving so that a handover can be managed. The family member is reassured that their relative will not be un-cared for and the resident may have the pleasure of hearing the staff member say something complimentary to reinforce the positive effect of the visit: "Are they your grandchildren, aren't they good-looking?" Or perhaps the resident can be diverted. "I've got such a pile of paper work to do, won't you come and keep me company while I make a start?"

If leave-taking is more than a furtive exit, relatives and staff might use the farewell to exchange any practical information that they've agreed to share, including any general observations or insights concerning the resident's well-being.

Suggestions:

- Acknowledge early that saying goodbye after a visit may be difficult for both resident and guest.
- Be ready to discuss helpful strategies to minimise this difficulty and reassure families and friends that their visits are worthwhile even when the person they have come to see seems angry or distressed when they leave.
- Give the processes of leave-taking equivalent consideration to the processes of arrival and alert staff to their potentially supportive role towards both guest and host.
- Encourage guests to be specific about their next visit – if this is possible.
- Consider ways of recording any contributions to care made by guests (two extra glasses of juice, for instance) including any observations ("She was rubbing her cheek a lot – I wondered whether she might have some discomfort there?").

In a video interview Michelle McCoughlin, Director of Nursing at Birmingham Children's Hospital (recently rated outstanding by the CQC) describes how she has instituted a space on every patient's daily observation chart to record family members' insights and why she believes family input is equally relevant in the care of vulnerable older people.¹⁴

Zoe Harris at My Care Matters used her experience as carer for her husband to develop charts that facilitate communication between families and care home or hospital staff and is continuing to develop these.¹⁵



3 Supporting Resident's Family and Friends

“When we welcome new residents into White Gables, we welcome their family too.” These are the first words of a John’s Campaign pledge. Problems do not vanish when someone moves into residential care – but at least they can be shared. Much of this support will happen informally as staff and family members get to know and trust one another. A relative or friend who has had a bad visit – finding the resident unreceptive or even hostile – is likely to experience this as a personal failure and take that feeling away with them. A small gesture of understanding from a staff member or offer to talk can have a disproportionately beneficial effect.

Even if the issues are too personal or painful for immediate discussion (long term family relationships are rarely all sunshine) the fact that the offer has been made is the beginning of comfort. Very often the staff member can help the guest see the distressing incident in the context of illness – and so less personally hurtful. This may help them find the resilience to return.

Family members may encounter difficulties with their own health or other relationships when a close relative has moved into residential care. This may be because they have previously been too busy providing daily support that they have not taken the time to follow up potential problems. Positive reassurance and understanding from the care home staff will be such a help in keeping guilt and anxiety at bay, allowing the family members the mental

space to deal with their own issues and then return, relieved.

Information stored in that invaluable guest pack may include referrals to carer support groups, encouragement to seek specialist advice (re finance for instance), signposting to locally useful services such as community transport.

Some care home managers arrange or advertise events for family carers to develop peer support relationships: others offer in-house insights on the progression of illnesses such as dementia. Regular, time-tabled, sessions to review the resident’s well-being will also provide an opportunity to ask the friend or relative how they are coping. Perhaps, at the outset, they accepted more specific care involvement than they now feel able to manage. Re-negotiate at once – it is their love and companionship that the resident needs, not their toe-nail clipping skills.

Janis Tunaley of the Orders of St John Care Trust explains how they use Admiral Nurses to provide specialist care to their residents with dementia and also support to families, often using Memory Cafes and involvement in Life Story work.¹⁶

Suggestions:

- Encourage staff to play their part in welcoming and getting to know visitors and understanding their point of view.
- Give staff the confidence to offer immediate human-scale sympathy and support if they notice that a family member or friend has been distressed by their visit.
- Offer family and friends opportunities to increase their understanding of dementia and any other conditions associated with illness or aging which might be affecting the quality of their interaction with their relative. There may be occasions when you can invite family or friends to staff training sessions.
- Where family and friends have chosen to be involved in personal care help them develop their skills as the resident's needs change, eg skincare if bed bound or feeding when swallowing becomes difficult. "Permit" them to give up personal care if it becomes too onerous.
- Signpost a range of external support organisations in your information pack eg carers groups, charities, citizens advice, local transport services.
- Be ready to facilitate any in-house initiatives – eg monthly tea party to help family members to get to know each other, perhaps including any volunteers or other befrienders.
- Institute your own regular catch-up timetable with the main visitor for each resident to ask them how they are as well as how the visits are going.



End-of life care – and “living with the legacy”¹⁷

Cicely Saunders (founder of the hospice movement) wrote: “You matter because you are you and you matter to the end of your life. We will do all we can to help you die peacefully but also to live until you die.” This is a great achievement for any care home. But Saunders also wrote, “How people die remains in the memory of those who live on.” If residents’ family and friends have not been welcomed, involved and supported during their relative’s life in residential care, the legacy will be either painful (filled with those negative emotions of anger, grief, guilt and resentment) or meaningless. Perhaps non-events, non-memories don’t signify? The novelist Margery Allingham wrote about involvement in the final years / months / moments of a close relative: “This is personal and private and exactly as important in one’s own story as one’s marriage or the birth of one’s child.”¹⁸

Many care home residents have died holding the hands of the staff members who have become their surrogate family because they have lost contact with the people who earlier in their lives had mattered so much. Other families have travelled from far away to be present at this moment – for their own sakes as well as for the sake of the person who has reached their last days.

In our society death is a rare experience for most people. When a resident is approaching the end of his or her life, the manager will need to be ready to brief close family members and friends as to what they may expect and how they can support their loved one’s passing with respect and dignity. If relationships to this point have been close and supportive – and inclusive of those who cannot be there in person

– the foundation for a good death has been established. If relationships have been less supportive and constructive, the approach of death offers a last vital opportunity to remedy this for the sake of those who will be “living with the legacy” – both family and staff. They will also not forget the importance of post-bereavement and even post-funeral support.

- Be ready with an individual plan of support when the resident approaches the end of their life. This must be based on the resident’s previously expressed wishes and augmented by all that you and your staff have learned about them and their family since.
- Communication and support is crucial but time-consuming. You may need to look at workloads to build this in.
- Do all you can to ensure that no one is kept away by previous ill-feeling.
- Recognise that some members of staff will also feel distress. Support them to attend the funeral if that is what they wish.
- Don’t underestimate the importance of practical and emotional post-bereavement support and a continued welcome (and involvement) if required.

Alison Hudson, manager of White Gables Care Home, Felixstowe, rated outstanding by the CQC and praised for its end of life care, recommends the Gold Standards Framework accreditation process but says the essential factors are developing staff attitudes and encouraging their willing involvement, whilst offering families practical and emotional support, honesty and the permission to be there or not as feels best to them.¹⁹

Moving On

Very many care homes that have been successful in building relationships with the families and friends of their residents find that some of the most regular guests wish to continue coming – perhaps as volunteers or even staff members. Alison Hudson still welcomes the wife of a former White Gables resident to have lunch with them every Sunday. Even those who never call again, but who have been welcomed and involved through that period of their family life, are likely to play their informal part in speaking well of the House in the community – which was probably where their journey began.

This may be an opportunity for us all in the current situation. We have an ageing population, a shortage of funds and a sense of impending crisis in health and social care. We have some hospitals that still shut out willing carers; we have exhausted family members struggling at home without respite and

we have a view of the residential sector that makes many people regard it as the Last Resort. Yet a resort is not such a bad place to go when you need recuperation, nurturing and Quality Time. How can we work together to recognise this and develop nurturing and inclusive communities which don't make us afraid or ashamed in our later years? I am my mother's regular guest in her Essex nursing home and I know that my life will never be the same again because of all I have learned from the goodness of care staff and nurses - and the endlessly fascinating company of residents living with dementia in the last stages of their lives.

George Coxon, owner of two care homes in Devon believes that providers should work together to raise standards and encourage people to look forward to spending their later years in residential care. As co-chair of the Devon Kite Mark Group he promotes the concept of family-friendliness beyond his own homes.²⁰

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