

# THE COMPASSION INTERVENTION MANUAL: A MODEL OF ENHANCED INTEGRATED CARE FOR PEOPLE WITH ADVANCED DEMENTIA

The Compassion Programme

(Care Of Memory Problems in Advanced Stages: Improving Our  
knowledge)





Developed by Marie Curie Palliative Care Research Department, University College London

Principal Investigator: Dr Louise Jones

Research Team: Dr Elizabeth L Sampson, Dr Margaret Elliott, Dr Kirsten Moore, Sarah Davis, Dr Jane Harrington, Dr Nuriye Kupeli, Sharon Scott, Victoria Vickerstaff, Anna Buylova Gola, Dr Bridget Candy

Co-Investigators: Professor Michael King, Division of Psychiatry UCL, Professor Irwin Nazareth, Primary Care and Population Health UCL, Professor Steve Morris, Health Economics UCL, Professor Rumana Z Omar, Biostatistics UCL, Professor Gerard Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster.

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# 1. BACKGROUND

Dementia is a progressive neurodegenerative disease. Approximately 850,000 people in the UK are currently living with dementia (1) and it is estimated that one in three people aged 65 years and over will die with dementia (2). The prevalence and incidence of dementia increase with age and the ageing population means these numbers are projected to increase further (3). People with dementia have a significantly increased mortality risk (4, 5) and in advanced disease symptoms of pain, agitation, distress, feeding difficulties, breathing problems and pressure sores are common (6-8). However, research suggests that for people with dementia essential components of good end of life care may often be neglected and referral to palliative care services is rare (9). Furthermore, people with dementia may die in acute hospital settings when this is not their preferred place of care and when aggressive or life sustaining treatments may no longer be effective or in their best interests (10). This means that people with dementia may not be receiving the care that they and their family would wish for at the end of life but also that avoidable and inappropriate acute health care costs may be incurred.

The National Dementia Strategy (11) was developed in recognition of the need to provide high quality services, support and information for people with dementia and for their family carers. This work is supported by NICE quality standards to guide the commissioning and delivery of services for people with dementia (12). These quality statements recommend firstly that, people with dementia should have an assessment and an ongoing personalised care plan agreed across health and social care that identifies a named care coordinator and addresses their individual needs; and secondly, that, people in the later stages of dementia should be assessed by primary care teams to identify and plan their palliative care needs. The Compassion Intervention is an enhanced model of usual care which aims to improve the care and outcomes for people with dementia approaching the end of life and meet the requirements of these quality standards.

## 1.1 Development of the Compassion Intervention

The Compassion Intervention is based on qualitative and quantitative research collected from people with dementia, their families, carers and healthcare professionals (13). It is underpinned by theories about how best to improve processes of care, incorporates what is known from international best practice and takes into account the complex interactions which may occur between people with dementia, their family carers, health and social care teams and the wider political and economic environment. The key aspects of the intervention have been developed in consultation with a wide range of health and social care professionals across all four countries of the UK and linked with key policy. An exploratory phase pilot study has been completed in two North London Care Homes (14).

## 1.2 Key components of the Compassion Intervention

- (i) Compassion uses an integrated, interdisciplinary whole systems approach to the coordinated delivery of person centred care across primary, secondary and tertiary settings and across specialist and generalist care. This is enabled by an Interdisciplinary Care Leader (ICL).
- (ii) Compassion employs a facilitation model for education, training and support to influence the behaviour of those caring for people with dementia. This involves working alongside care home staff to develop a culture of respect, dignity and quality of care for all residents and their family carers living with dementia and to increase understanding of the natural history, symptom burden, palliative and end of life care needs of people with dementia.

Compassion aims to enable effective and sustainable change in the context of the local requirements and where appropriate to influence change in the wider economic and political environment.

## 1.3 Outline of the Compassion Intervention

The focus of the enhanced care model will be within care homes as this is where current evidence suggests need is greatest. However, it may be possible to extend implementation into the wider community once an effective working model is established. The intervention aims to improve end of life care for people with dementia by:

- Providing an interdisciplinary care leader (ICL) who will act as a central resource for health and social care professionals, care home staff and family or informal carers involved in the care of people with dementia;
- Developing joint working between all those involved in the care of people with dementia to establish a model of integrated care;
- Improving the understanding of what is meant by a personal care plan and how such a plan might be worked out and used in practice to enable holistic person centred care;
- Providing support to front-line staff in care homes to enable them to hold uncertainty and manage risk in people with dementia to avoid unnecessary place of care transfers;
- Identifying, facilitating and supporting the training needs of care home staff involved in the care of those with dementia;
- Recognising the needs of family or informal carers and providing appropriate information and support;
- Collecting data to support the commissioning of effective and sustainable systems to deliver these objectives.

## 2. DELIVERY OF THE COMPASSION INTERVENTION

The Compassion Intervention aims to integrate change within existing systems and to develop an understanding of what is needed within each locality to enable the delivery of high quality care to meet local service requirements and quality standards for dementia and end-of-life care.

### 2.1 Compassion Intervention: The key people

#### Interdisciplinary Care Leader (ICL)

The responsibilities of this new post will include:

- Developing an understanding of the health and social care professionals, pathways and services relevant to the care of people with dementia available in the locality;
- Working with care home staff to identify and support educational and training needs;
- Working with care home staff to identify and assess residents suitable for inclusion in the enhanced care service;
- Working with a core team to co-ordinate a regular/weekly meeting and to develop personal care plans for each resident included in the intervention;
- Working with the wider interdisciplinary team to co-ordinate a regular/monthly meeting and to provide effective integrated interdisciplinary care;
- Meeting with family carers to ensure their needs and wishes are understood and to provide information and support;
- Collecting data to support evaluation and further development of the intervention.

#### The Core Team

This team is responsible for the medical, nursing and social care needs of residents participating in the intervention. We suggest the team meet weekly and include:

- The Clinical Lead Professional who has ultimate responsibility for the medical care of the resident (GP, Geriatrician or Old Age Psychiatrist);
- A member of the care home staff who has responsibility for the nursing and social care needs of the resident (care home manager or floor/dementia unit manager);
- Interdisciplinary Care Leader;
- Other key workers closely involved in the resident's care could also attend, including nursing staff and/or healthcare assistants.

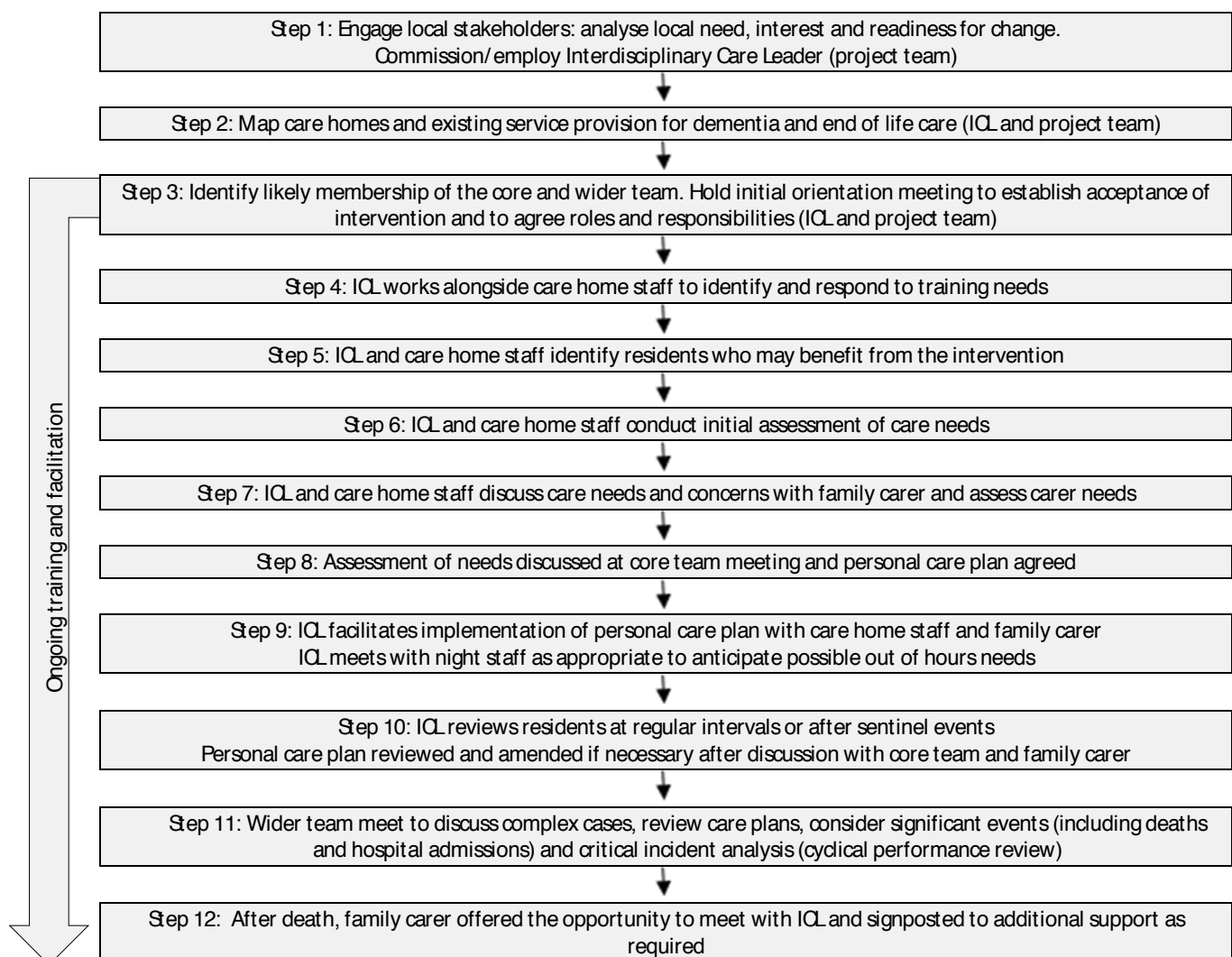
#### The Wider Team

This team will provide specialist and interdisciplinary support and is likely to include representatives from Care of the Elderly, Old Age Psychiatry, Palliative Care, community services such as Speech and Language Therapy, Dietetics, Physiotherapy and Occupational Therapy, and Social Services. However, the exact composition will depend on local working practices and the availability of key personnel. We suggest the wider interdisciplinary team

meet monthly with the core team; meetings may be face to face or via links such as conference calling.

## 2.2 Compassion Intervention: The steps required

The Compassion Intervention flow chart outlines the steps of the intervention and the roles and the responsibilities of those participating in the enhanced care service.



**Step 1:** The commissioning lead/ project team presents the Compassion Intervention to decision makers within the Clinical Commissioning Group (CCG) who have an interest in end of life, frail elderly and dementia care to explain the rationale behind the enhanced care model and to gain their support. The project team liaise with local service providers and care home providers within the participating CCG to assess current needs and readiness for change. The new post of Interdisciplinary Care Leader (ICL) is commissioned; this could be



from within existing teams, such as palliative care or community mental health, or from outside agencies such as those within the third sector. Step 1 is discussed in greater detail in Section 3: 'Organisational and Commissioning Considerations' (page 10).

**Step 2:** The ICL and project team will map local care homes and existing service provision for dementia and end of life care. This should include consideration as to whether the CCG is meeting its current service requirements and quality standards in order to identify any specific gaps or concerns which may need to be addressed by the enhanced care model. The practical actions required to implement and run the intervention should also be identified. Step 2 is discussed in greater detail in Section 3: 'Organisational and Commissioning Considerations'.

**Step 3:** The project team and ICL will identify potential members of the core and wider teams. An orientation meeting should be held to discuss the role of the Interdisciplinary Care Leader, the aims of the Compassion Intervention, the processes required to implement the intervention, the purpose of the core and wider team meetings and the requirements to enable meetings to occur. The orientation meeting will aim to establish initial acceptance of the enhanced care model and agreement as to the configuration of the core and wider teams. Further meetings may be required to consider details such as individual roles and responsibilities, the organisation of meetings, methods of communication, record keeping and how to access support between meetings if required. Step 3 is discussed in greater detail in Section 3: 'Organisational and Commissioning Considerations'.

**Step 4:** The ICL will arrange with the care home management to work alongside the care home staff to establish the aims and purpose of the intervention and help to address any immediate educational and training needs. This should include engaging with staff covering both day and night shifts and working with staff of all levels of seniority. Training should continue throughout the intervention and is an integral part of the enhanced care model and ICL role. This is likely to include training to respond to common needs identified during residents' assessments and considering the educational/information needs of family carers. Step 4 is discussed in greater detail within Section 4: 'Education and Training' on page 14.

**Step 5:** The ICL will work with care home staff to identify all residents within the care home suitable for inclusion in the enhanced care model. The suggested inclusion criteria for the Compassion Intervention are derived from research evidence (14, 15) and describe those participants most likely to benefit from enhanced care. However, components of the Intervention may be useful for other residents with dementia and this requires further field testing and investigation.

**Inclusion criteria:** A diagnosis of moderately severe or severe dementia or severe memory problems indicating a clinical diagnosis of dementia plus at least one of the following criteria:

- ❑ Physical frailty, significant weight loss, poor nutrition level, recurrent infections or fevers, falls, pressure ulcers or pain that are not easily amenable to treatment;
- ❑ Severe persistent distress (mental or physical) that is not easily amenable to treatment;
- ❑ Another condition (e.g. co-morbid cancer, advanced frailty) whose co-existence with dementia means that a palliative approach should be considered.

**Step 6:** The ICL will work with care home staff to assess the current care needs and symptoms of each resident identified as suitable for inclusion in the intervention. This should include consideration of any factors which suggest the resident's condition may be changing and anticipating possible future needs or events. Detailed instructions to support this assessment are contained within Section 5: 'Holistic Assessment Guidance' and a checklist and example assessment template is provided in Appendix 1. A template for the personal care plan is included in Appendix 2 along with a review care plan template in Appendix 3.

**Step 7:** The ICL and care home staff should make active efforts through the usual channels to meet with family carers to discuss any care needs identified and to understand any further concerns which the family may have. Family carers should also be offered the opportunity to discuss future care preferences and wishes with regard to end of life care; information to support such discussions is contained in Section 6: 'Guidance for collaborating with residents' family and friends'. Family carers' needs and concerns should be added to the resident's assessment for discussion at the core team meeting.

Throughout this process the ICL and care home staff should be alert to the needs of the family carers themselves, including the possibility of anxiety and depression, as consideration of carer needs may not currently be an element of routine practice. If needs are identified, family members should be offered appropriate support and signposted to additional resources as required.

**Step 8:** The ICL and care home staff will discuss the findings of the assessment at the core team meeting with the Lead Clinical Professional. The core team meeting should take place at the care home so that the lead professional can assess the resident personally and meet with family carers if required. The meeting should include:

- ❑ Discussion regarding areas of identified unmet symptom or care need;
- ❑ Formulation of an action plan to address each area of unmet need, including setting goals for treatment and a review date;
- ❑ Discussion of anticipated needs and possible future events with development of an action or escalation plan for the most likely "what ifs";
- ❑ Review of current medication and alterations made if required;
- ❑ Consideration of the need for anticipatory prescribing;

- Review of end of life wishes and resuscitation status to ensure that whenever possible these decisions are clearly documented. It is likely that the resident will lack the mental capacity to make these decisions for themselves but this should be assessed as per the Mental Capacity Act (2005) so that if necessary decisions can be made in the resident's best interests and reflect their wishes and/or those of their family;
- Consideration as to whether discussion with the wider team would be helpful;
- Setting a date for next review.

**Step 9:** The core team should agree a personal care plan and summary of actions required (Appendix 2 template). The team should ensure that plans are effectively communicated to care home staff and family carers. It is essential that both day and night staff feel supported and able to work to these plans and that family carers understand and are in agreement with the personal care plan. There should be a particular emphasis on ensuring plans are in place to cover problems that may arise outside normal working hours, overnight and at weekends, in order to help staff to reduce inappropriate place of care transfers. The ICL should support care home staff in delivering the agreed care plans and ensure that outcomes are reviewed. Personal care plans should be accessible to any health care professional visiting the resident within the care home and when appropriate, with the necessary permission, should be shared with other agencies, such as electronic palliative care records, out-of-hours providers and the ambulance service.

**Step 10:** The ICL and care home staff should meet at regular intervals to review residents so as to ensure early identification of any changing needs. They should also continue to identify new residents, or existing residents whose condition may have changed, suitable for inclusion in the intervention. Throughout this process the ICL and care home should maintain regular contact with family carers so that they are aware of any changes in the care or health of their loved one and so that their views and concerns are known. The core team should review and consider any such changes so that personal care plans can be amended appropriately.

**Step 11:** The core team should meet regularly with the wider team in order to discuss residents who have complex needs requiring specialist advice or interdisciplinary support. Initially it may also be useful to discuss a wider range of cases, including those where management seems more straightforward, in order to ensure cases are being managed appropriately, to an agreed standard of care, and to consolidate good practice. The ICL should ensure that action plans agreed by the wider team are communicated, implemented and recorded as per previous detailing and that outcomes are reviewed and report back to the wider team.

A further function of the wider team meetings should be to consider any learning or training needs that may become evident as a consequence of this shared working. This should include

discussion of significant events and critical incidents, such as deaths, hospital admissions, complaints or compliments, so that learning points can be identified. An appropriate strategy should be developed to disseminate this learning to the whole team and implement any changes required. It is important that both positive and negative events are discussed in order to build on examples of good practice as well as to identify areas for improvement.

**Step 12:** Following the death of a resident the family carer should be offered the opportunity to meet with care home staff, and/or the ICL, in order to offer bereavement support and signpost to any additional services as appropriate.

In addition to the above, the ICL, care home, core and wider team may be required to record data to enable monitoring and evaluation of the intervention. The specific requirements for this will be determined by the commissioning group in line with stated outcome measures, key performance indicators and quality standards.

## 3. ORGANISATIONAL AND COMMISSIONING CONSIDERATIONS

There are a number of key organisational and commissioning areas that need to be considered for the effective implementation and running of the enhanced care service.

### 3.1 Analysing local need

Commissioners will need to define the local need for end of life care in dementia. There are a number of tools available to support this. The Dementia Prevalence Calculator can be used to develop a local estimated prevalence of dementia in the community and among people living in local care homes. <http://www.dementiaprevalencecalculator.org.uk/>

End of Life Care Profiles compare the position of the CCG or Local Authority with others in England. They show indicators of end-of-life care need in table, chart and map format using the Instant Atlas mapping tool and can be used to track that position over time. [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/)

The Marie Curie Atlas Mapping tool offers insights into care provision within a given area by bringing together a broad range of data on end of life care. <http://www.mariecurie.org.uk/en-gb/Commissioners-and-referrers/Resources/Marie-Curie-Atlas/>

### 3.2 Service requirements and Key Performance Indicators

Commissioners will need to identify current service requirements, key performance indicators (KPI), quality standards and any issues specific to the local area of importance for dementia and end of life care. Consideration as to whether the CCG is meeting these requirements and whether there are areas which require improvement are integral to developing the enhanced care service, the role of the Interdisciplinary Care Leader (ICL) and in setting outcome measures to evaluate the effectiveness of the intervention. This process should include assessment of current service provision and any gaps therein which may need addressing to support the implementation of the intervention.

NICE Dementia: support in health and social care Quality Standard 1 (12) includes a number of Quality Statements that may be pertinent to end-of-life care:

- Quality Statement 1: People with dementia receive care from staff appropriately trained in dementia care.

- Quality Statement 4: People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.
- Quality Statement 5: People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: advance statements; advance decisions to refuse treatment; Lasting Power of Attorney and Preferred Priorities of Care.
- Quality Statement 6: Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
- Quality Statement 7: People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
- Quality Statement 9: People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

There are a number of key issues which may affect how older people with dementia and palliative care needs are managed within the local area:

- The number of care homes which have Gold Standards Framework (GSF) accreditation (16) or have participated in other training programmes such as those linked to the National End of Life care Programme “The route to success in end of life care: achieving quality in care homes” (17).
- Whether the local palliative care team or hospice has non-cancer palliative care outreach programmes
- Whether integrated care models for frail older people are currently in use
- Whether an electronic end of life care register is available

### 3.3 The post of Interdisciplinary Care Leader

The role of the Interdisciplinary Care Leader (ICL) has been outlined earlier in this manual; however, the exact job specification will depend on the requirements identified by the CCG during the review of current service provision. The post could be suitable for a senior nurse with experience in either palliative care, mental health or care of frail older people, or for a senior allied health or social care professional, such as a physiotherapist, occupational therapist or social worker with experience of working with dementia or frail older people. Consideration as to the person specification required is likely to influence whether the post is commissioned from within existing community teams, such as palliative care or mental health, or from outside agencies such as those within the third sector. The host team

commissioned to provide the enhanced service should be responsible for training the ICL in standard procedures with regard to clinical and information governance, safeguarding of vulnerable adults and the Mental Capacity Act prior to commencing in post. They will also be required to provide ongoing support, training and professional development, monitoring and regular appraisal for the role. The background of both the ICL and the host team will to a certain extent influence the emphasis or priorities for the enhanced care service within each local area.

The number of care homes appropriate for the ICL caseload will be dependent on the requirements and objectives identified by the CCG, as well as factors such as the size of the care home, their existing experience or skills in managing dementia and end of life care, and the degree to which interdisciplinary services are already involved in supporting the home. However, we suggest that there is likely to be an initial period of approximately three months when the ICL will need to work more intensively with the care home, for example 2-3 days per week, to implement and establish the intervention. Following this contact may be reduced but is likely to require a minimum of 2 sessions/half-days per week per care home to enable review of existing residents, assessment of new residents, meetings with family carers, attendance at core team meetings, collection of evaluation data and provision of training sessions.

### 3.4 Engagement with local stakeholders

The project team and ICL will need to identify and contact all care homes within the locality to provide information regarding the enhanced service. They will need to establish which care homes are interested and willing to participate in the intervention; particular consideration should be given to identifying and engaging with care homes which may have most need for additional training and support. Following this the project team and ICL will need to identify and contact the potential Lead Clinical Professional and wider interdisciplinary team responsible for providing care and support to each home. An orientation meeting should be held with these service providers to discuss the role of the ICL, the aims of the enhanced care model, the processes required to implement the intervention, the purpose of the core and wider team meetings and the requirements to enable meetings to occur. The orientation meeting should aim to establish acceptance of the enhanced care model and agreement as to the configuration of the core and wider teams. Further meetings may be required to consider details such as the organisation of meetings, methods of communication, record keeping and how to access support between meetings if required. Meetings should also aim to identify any additional funding, time, personnel, expertise or resources that will be required to establish, implement and deliver the enhanced service.

It is likely that interdisciplinary teams will span primary and secondary care, mental health services, community services and social services. Effective communication and integration of these different services is integral to the successful implementation and running of the enhanced care service. Key areas of interface will vary between different locations but are likely to include linking with existing primary care systems to co-ordinate the care of frail older people, such as multidisciplinary meetings, “virtual ward rounds” and case conferences; linking with out-of-hours care to access existing systems designed to enhance communication, such as Electronic Palliative Care Co-ordination Systems; linking with social services through usual channels of referral when unmet social care needs or concerns are identified. Consideration will also be required as to whether one interdisciplinary team could provide support to a number of individual core teams/care homes and this will be influenced by the logistics of the geography and service configuration within each area. A timeframe and expected schedule should be established and any written agreements or Service level Agreements (SLAs) for the intervention to be implemented should be generated between commissioners, care homes and local service providers.

### 3.5 Monitoring and evaluation

Commissioners and service providers will need to agree systems for monitoring, audit and evaluation of the intervention. This should include defining what data collection is required, by whom and over what time frame, and how this will be evaluated to assess the impact of the intervention in meeting the required objectives. Mechanisms should also be considered for recording financial costs and savings associated with the enhanced care service to establish economic sustainability. Systems for clinical governance, information governance, safe guarding and quality assurance should follow the standard procedures of the lead local organisation.



## 4. EDUCATION AND TRAINING

Existing education and training programs in end of life care for people with dementia within the local area should be identified by the ICL and project team and whenever possible training and support programmes developed as part of the intervention should aim to integrate with these systems. The ICL should work with the care home to identify the training and educational needs of staff members. These may then be addressed by the ICL in a variety of ways to suit individual learning styles and needs but are likely to include shared working, mentoring, the use of online learning resources and formal topic based teaching sessions. It is envisaged that the lead clinical professional and wider team will support the ICL in this role, particularly in relation to learning needs identified from significant events and where the area of training falls within their specialist knowledge. Training should be feasible within timing, staffing and financial constraints and should be agreed with the care home manager. It should aim to enable staff to recognise and respond effectively to the needs of people with dementia and their family carers and should link to nationally agreed core competencies in end of life care (18) including:

- **Assessment and care planning**, to develop holistic assessment and person centred care planning which includes recognition of family carer wishes and needs
- **Symptom management**, to improve the management of common symptoms such as pain or psychological distress, using appropriate assessment tools and referral for advice when required, so as to ensure as far as possible the maintenance of comfort and wellbeing
- **Advance care planning**, to support staff in developing the skills required to talk to residents and family carers about future care preferences and advance care plans
- **Communication skills**, to enable effective and empathetic communication with residents and their family carers
- **Knowledge and values**, to develop an understanding of dementia and how this may affect people towards the end of life; to identify their own and colleagues training and support needs; to increase awareness of specialist services available to offer additional support; to ensure that residents and family carers are treated with respect, dignity and the highest quality care at all times.

The ICL should also be available to provide information and education to family members; this may be on an individual basis or in small group sessions. Topics likely to be appropriate are understanding dementia and the disease progression, information about common symptoms and management strategies, and consideration of future care preferences, advance care plans and end of life wishes.

## 5. HOLISTIC ASSESSMENT GUIDANCE

The holistic assessment guidance includes key issues which have been identified in studies of people with advanced dementia and that may be important for the effective management of symptoms and maintenance of comfort (6-9). It is based on the principals of the comprehensive geriatric assessment and guidance within the holistic common assessment of supportive and palliative care needs for adults requiring end of life care (19). Assessments should be completed by the ICL, supported by the care home staff, and will form the basis of discussions at the core team meeting in order to develop a personal care plan for each resident. This guidance is not exhaustive and other factors specific to each resident may need to be considered. The holistic assessment is likely to include elements of existing assessments undertaken by care homes. Appendix 1 includes two options:

1. A checklist in which services can evaluate their existing assessment processes to ensure that all relevant items are currently being assessed.
2. A brief summary two page assessment template to record the holistic assessment. This could be used or adapted and may include attachments to other more detailed assessments, such as a depression screen or observational pain assessment tool.

An example personal care plan is included in Appendix 2. Appendix 3 includes a template for a review assessment template, however, services may prefer to use or adapt existing local documentation.

### 5.1 Compassion Holistic Assessment

#### Background information

This should bring together basic information including resident details, significant past medical history, current medication, recorded end of life wishes and professionals and family members involved in providing care and support. It is particularly important that details of the key family members and/or friends who know the resident best and are involved in decisions about their care are recorded. This should include whenever possible who would like to be contacted if the resident's condition were to alter and if any family member holds Lasting Power of Attorney for Personal Welfare giving them the legal right to give or refuse consent for medical treatment on the resident's behalf.

#### Communication

Residents with advanced dementia may have limited ability to communicate or understand what is communicated to them. Assessment of communication may include how many words the resident is able to speak and if these are used appropriately, whereas assessment of understanding may include response to a simple question or the ability to follow a simple

instruction. If the resident has no meaningful language then direct observation and the opinions of those intimately involved in their care may be required to assess symptoms and comfort. If understanding is limited then simple verbal or non-verbal communication, such as hand gestures, tone of voice, eye contact and smiling may be helpful in conveying meaning. Considering communication difficulties may be particularly important when assessing symptoms of pain or distress, in order to maximise understanding of what the resident might be experiencing.

### Pain or discomfort

There is no evidence that people with dementia experience less pain than others but they are typically less likely to be prescribed pain killers, meaning that the experience of pain may often go unnoticed or undertreated (20). People with dementia may have difficulty communicating that they are in pain and/or interpreting pain signals, so that pain may manifest itself as agitation, distress, social withdrawal, depression or resistive behaviour. Direct observation and the use of validated observational pain scales such as the Pain Assessment in Advanced Dementia [PAINAD] scale (21) (See Appendix 4). A PAINAD score of 2 or more can be used as an indicator of probable pain. A score of 1 is a sign to be attentive to possible pain (22). Also seek the opinions of family members and care staff most closely involved in the resident's care. Common causes of pain to consider are listed in the table below.

Causes of Chronic pain	Causes of Acute pain
Awkward positioning	Gastrointestinal pain
Increased muscle tone & contractures	Urinary retention
Pressure areas & pressure sores	Acute infection e.g. pneumonia/UTI
Arthritis & joint pain	Skin or wound infections/dental abscess
Constipation or indigestion	Undiagnosed fracture
Skin irritation, itching or soreness	Deep vein thrombosis
Dental disease/poor dentition	Angina or myocardial infarction

Sometimes it may not be possible to identify the source of the pain or to relieve its cause fully. Non-pharmacological measures such as repositioning, pressure relieving aids, physiotherapy or massage should be considered but if these are not effective a trial of pain killers may be appropriate. Simple analgesia such as paracetamol prescribed on a regular basis can be very effective (6); however, stronger analgesics, including opiates, may need to be considered.

## Mental health, behavioural and psychological symptoms

Behaviours similar to those seen when a resident is experiencing physical pain may also occur with emotional or psychological pain, frustration, boredom or distress. Depression and anxiety are frequently associated with dementia. If a resident appears tearful, sad or withdrawn assessment by completing the Cornell Depression in Dementia Scale may be helpful (23). Measures to support the resident, such as increased social engagement and involvement in activities should be tried, but if these do not appear to alleviate symptoms a trial of anti-depressant medications may be considered. In some people with dementia more serious symptoms such as auditory or visual hallucinations or paranoia may be occurring. If these are suspected then referral to and advice from the mental health team may be required.

Behavioural and psychological symptoms of dementia (BPSD) occur in up to 90% of people with dementia at some time during the course of their illness. In early stages there may be wandering, personality changes, disinhibition or outbursts of aggression, whereas in later stages over 50% of people may display symptoms of agitation and distress (6, 7). The management of BPSD can be challenging, however, a structured approach using a simple “ABC” analysis can reveal patterns and triggers and help with considering and testing solutions (24, 25). This involves documenting the Antecedents of the behaviour (what led up to it and might have caused it?), the Behavioural disturbance (what actually happened?) and the Consequences of the behaviour (what effect did it have?). Possible causes of agitation and distress are listed in the table below.

Biological	Psychological	Social
Pain or discomfort	Depression or anxiety	Under-stimulating environment, boredom, frustration, immobility
Infection, adding to pain or confusion	Disorientation or confusion	Over-stimulating environment, too noisy, threatening or confusing
Hearing or visual loss adding to isolation and confusion	Loneliness or sadness, missing family or friends	Isolation, , hunger, lack of exercise, lack of dignity, privacy or ability to communicate needs or feelings
Medication side effects	Existential distress	Environment, temperature too hot or too cold, draughty or uncomfortable

The disorientation and confusion that occurs with dementia may mean residents believe that they are being held in a strange place against their will or that they need to get home to care for children or relatives; aggression and resisting personal care may be indicators of untreated pain. Simple strategies such as approaching the resident slowly, showing them what is going to happen and gentle reassurance may be helpful; environmental modifications, such as limiting noise or playing quiet music and ensuring that the resident is physically comfortable

should be considered. Including the resident in communal activities may reduce loneliness and boredom, whilst taking them for a walk or enabling them to sit outside in a garden may reduce frustration and agitation; assessing the need for glasses or hearing aids may improve communication and reduce isolation and confusion. However, analysing behaviours can be complex and further advice and support may be required from the mental health team; in severe agitation or distress antipsychotic medications may need to be considered but these should only be initiated under specialist supervision.

### **Mobility, tone and contractures**

In advanced dementia mobility will usually be limited. For those who are able to walk there is an increased risk of falling due to impaired balance and co-ordination as well as a reduced awareness of environmental factors and safety. For those no longer able to walk, reduced muscle strength and generalised weakness may lead to difficulties with maintaining posture whilst sitting in a chair or bed and they may be unable to alter their position without assistance. These factors increase the risk of injury or pressure sores and advice from physiotherapy or occupational therapy may be helpful to improve comfort and anticipate or prevent future problems. People with advanced dementia may also develop increased muscle tone and stiffness, which can further reduce independent movement, cause discomfort and the development of contractures. Flexion contractures typical occur in the hand, with a clawing of fingers, and in the legs, with the knees being drawn up towards the body. The risk of contractures problems can be reduced by careful positioning, massage, gentle stretching exercises and physiotherapy; medication to reduce muscle tone may be considered.

### **Pressure sores and skin condition**

Pressure sores are common in people with advanced dementia. They cause pain and a resident may need to stay in bed to promote healing and so miss out on communal activities. Pressure sores typically take a long time to heal and involve considerable time from nursing staff to dress and treat. Whilst it is impossible to prevent all pressure sores, careful attention to skin care can reduce the risk of these developing. Most care homes will already have systems in place for monitoring the occurrence of and managing pressure sores. The Waterlow Scale (available from: <http://www.judy-waterlow.co.uk/the-waterlow-score-card.htm>) can be used to identify residents who are at particular risk; vigilance for warning signs such as dry skin, redness, trauma, oedema and infections, which may threaten skin integrity, is important. Early intervention with pressure relieving aids, creams and appropriate medications or dressings can be helpful. In complex cases referral to local tissue viability nurses specialist may be required.

### **Continence, urinary and bowel problems**

Urinary and faecal incontinence are common in advanced dementia; however, individuals may retain some awareness of the need to empty their bladder or bowels which can cause distress or agitation. Soiled pads may cause irritation or skin soreness, whilst residents who are catheterised may try to remove the catheter causing trauma and pain. Urinary tract

infections (UTIs) are common and some people may be particularly prone to develop these. Residents suffering UTIs are unlikely to be able to communicate their symptoms directly and so may express these in altered behaviours, such as confusion or agitation, or they may appear generally less well, with reduced appetite and increased sleepiness. Checking for a urine infection by collecting a midstream urine sample is the best method of assessment but this is often not practical if someone is incontinent. The urine may have a distinctive odour suggesting an infection or be discoloured; a urine testing strip can be held against a wet pad but this will frequently show a positive result and does not necessarily confirm an infection. Often it is the combination of features that makes the diagnosis of a UTI likely and a trial of antibiotics may be appropriate. Simple measures such as keeping the perineum as clean and dry as possible and encouraging fluid intake may help to reduce infections. In male residents it is important to consider the possibility of prostate problems and urinary retention.

Constipation in dementia is similarly common. This may lead to abdominal cramps and discomfort, pain on defecation, reduced appetite and can exacerbate difficulties in passing urine. Monitoring bowel movements using stool charts can help to pick up such problems. Encouraging fluids and dietary fibre can be helpful but laxatives may be required to maintain regular bowel function.

### Swallowing problems, weight loss and nutritional status

Eating and swallowing difficulties occur frequently as dementia progresses. People with advanced dementia may fail to recognise previously familiar foods and may lose the normal physiological drivers of appetite and hunger. The physical action and co-ordination of chewing food (oral phase dysphagia) and swallowing (pharyngeal phase dysphagia) are commonly affected and chewing problems may be exacerbated by poor dentition or dental pain. Food which is not adequately chewed before swallowing may lead to an increased risk of choking and swallowing difficulties may lead to a risk of aspiration and chest infections. A possible indication of swallowing difficulties and aspiration is coughing when eating and further assessment by a speech and language therapist (SALT) may be required. Swallowing difficulties can be helped by careful positioning during mealtimes, allowing enough time for the resident to eat and altering the consistency of food by softening or pureeing solids and thickening fluids. Whilst these measures can reduce the risks of choking and aspiration it is important that staff and family are aware that these problems could still occur despite all best efforts.

Weight loss is common in advanced dementia (6, 7). Identifying favourite foods, allowing time for the resident to eat at their own pace and considering smaller more frequent meals may be helpful; referral to a dietician for advice on maximising the intake of calories and essential vitamins and nutrients may be necessary. However, weight loss may be a sign of disease progression or indicate that there is additional undiagnosed pathology; as weight loss progresses the resident may become weaker and be more at risk of developing infections,

pressure sores or other adverse events. Maintaining adequate nutrition and hydration can become increasingly difficult in the advanced stages of illness and problems with this may indicate imminent dying; this can be upsetting for family and care staff and referral to the palliative care team may be helpful in providing additional support.

#### Other problems, sentinel events, symptoms suggesting change

There may be other problems specific to each individual resident that are important to consider. For example, there may be a risk of recurrent chest infections or of fits or “funny turns”. It can be helpful to think through such events to identify any triggers and consider any preventative measures or actions that could be taken to improve the resident’s comfort.

A hospital admission, infection or fall, in someone with advanced dementia may indicate that they are at increased risk of further events or to deterioration in their general health. Signs and symptoms suggestive of deterioration may include reduced appetite and weight loss, reducing mobility or increasing weakness, and spending more time asleep or in a withdrawn or lethargic state; often there may just be a sense that something is not quite right. In these circumstances it may be helpful to explore the perceptions of family carers and to prepare them for the possibility that their loved ones condition may be changing. If there is concern that a resident is nearing the end of life, appropriate supportive measures can be put in place and a referral to the palliative care team considered.

## 5.2 Compassion Personal Care Plan

The personal care plan should be completed by the core team following the holistic assessment. It should aim to include details of the goals of care, of current and anticipated care needs and to review current medications or treatments to ensure they remain appropriate. Whenever possible the care plan should be discussed with family members. See Appendix 2 for a personal care plan template.

### Goals of care and end of life care wishes

Goals of care and end of life wishes should be discussed with the resident personally if possible. However, most people with advanced dementia will lack capacity to make decisions about their care and it is likely that such discussions will be held with family carers. Advance care plans or advance decisions to refuse treatment (ADRT) already made should be reviewed and any concerns not previously documented discussed. If clear advance care plans have not been made then family carers should be offered the opportunity to discuss these and to consider what they believe their loved one would have wanted at this stage of their illness. Such discussions should include consideration of any spiritual, religious or cultural issues of relevance. Further guidance on having these discussions is contained in Section 6.

### Areas of unmet and anticipated need

The holistic assessment aims to identify areas of unmet symptom need and to consider whether there is an increased risk of future events such as falls, chest infections or seizures. The personal care plans should aim to define any actions that are required to address these needs, the desired outcome/result of these actions and when they should be reviewed. Plans should support care home staff to manage the resident safely and effectively and reflect the goals of care identified during discussions with the resident and/or their family carer. This may include establishing a ceiling of care, advice as to when it would be appropriate to call for support or hospital admission, or when it may be more appropriate to manage a condition within the care home, including the use of anticipatory prescribing.

### Medication review

Medication should be reviewed to ensure that this remains appropriate for the resident's current needs. This may include consideration as to whether any medication may be causing side effects, such as confusion or constipation; if medications prescribed for disease prevention, such as statins and ACE inhibitors remain appropriate; if medications prescribed on an as required basis, such as analgesics or laxatives, are required regularly, and whether confusion or swallowing difficulties may limit compliance. In addition the need for anticipatory prescribing should be considered.

Personal care plans should be reviewed regularly or if the resident's condition changes (See care plan review template at Appendix 3).



## 6. GUIDANCE FOR COLLABORATING WITH RESIDENTS' FAMILY AND FRIENDS

### 6.1 Why it's important to talk to family and friends about end of life care in dementia

NICE quality standards relating to dementia recommend that people with dementia have the opportunity to discuss future wishes, such as decisions to refuse treatment, when they still have capacity to do so (12). During mild stages of dementia people may have difficulty imagining a future self which is more dependent on others (26) and during advanced stages communication becomes very limited. Family and sometimes close friends may become proxy decision makers for someone during advanced stages of dementia. Talking about death and dying is a difficult topic to raise (27) and family and friends may need support and prompting to have these conversations.

Family carers may regret not having had these discussions earlier and not having had more specific discussions about medications and nutrition (28). Religious beliefs, education, guilt, burden and assumptions about quality of life can influence family member's choices about palliative care and may prevent them making decisions in the best interests of their relative (29). However, there can be improved outcomes for residents when family carers understand the progression of dementia. A nursing home study of advanced dementia found that when family members believed their relative had less than six months to live and understood likely clinical complications, the person with dementia was less likely to receive a burdensome intervention during their last three months of life (6). Another study found that while only 43% of family members reported dementia as a disease you can die from, agreement with this statement was associated with higher resident comfort at end of life as assessed by the physician (30).

### 6.2 Having routine regular reviews with family and friends

Before discussing issues about the future it is important to first discuss any current issues that the family member or friend has. It may not be productive to discuss the best care to provide in the future if family and friends do not feel that the resident is currently receiving high quality care. Findings from earlier stages of the Compassion study found that some carers wished to have regular updates about their relative's health and the progression of dementia, preferably with a key contact person who was responsible for the resident's care and who knew the resident well. Not all family and friends may want to have these discussions but giving them the option may help them feel informed and involved in care.

The holistic assessment described in this manual can be used as the basis for these discussions. Regular discussions may have a number of benefits and may help care home staff educate families about how dementia may progress. For example, discussing common changes in appetite and swallowing in advanced dementia may help explain potential weight loss and increased chest infections. Discussions may help identify issues where family may need some more information and support. Helping family understand common symptoms may help alleviate their concerns about the quality of care.

### Some tips for having a conversation

Some basic principles to keep in mind when discussing end of life care with family and friends of residents:

- Choose a quiet and private space where you are unlikely to be disrupted or overheard.
- Give the family member genuine time and attention.
- Try to avoid euphemisms and vague terms as some words and phrases may not translate well to people of different age, culture, language or religion.
- Offer an opportunity to have a discussion, but respect that they may not be ready to have this discussion. Make it clear that they are welcome to revisit the discussion again or to postpone it to another time when they are ready.
- Provide reassurance and remind them that planning can make things easier in the future.
- Acknowledge your own fears and concerns about having these conversations.
- Remember you don't need to have all the answers; just being a good listener may be helpful and provide the family member with an avenue to express their fears and concerns. You can always offer to find information you do not have on you at the time.
- Be sensitive as well as honest; offering false hope can be distressing for family if death is unexpected and they feel unprepared.
- Provide them with written information they can read in their own time as a supplement to discussions. There are a number of useful resources from the organisation websites listed at the end of this section (6.5) that covers issues such as common symptoms of advanced dementia, coping with grief and dealing with legal and practical issues at end of life.

## 6.3 Documenting decisions

Having decisions in writing may be important from a health professional's perspective, but family may worry about and avoid putting things in writing. They may feel a sense of finality about documenting decisions and that there is no room to change a decision once it is in writing. Ensure that the family is aware that decisions made in writing can and should be reviewed and revised from time to time, taking into consideration changing circumstances and the best interests of the person with dementia. Remember that there can be benefits

from a conversation even when decisions are not documented. And while family members may not be ready to document decisions at a first discussion, opening up the conversation may help them to feel more comfortable putting things in writing in subsequent discussions.

Cardiopulmonary resuscitation in people with advanced dementia is unlikely to be successful (31) and is likely to cause harm such as rib and sternum fractures (32). While you may view completing a Do Not Attempt Resuscitation form may be in the best interests of the resident, family may view this as 'giving up' on their relative and this may trigger feelings of grief and guilt. It is critical that they are well informed about what resuscitation would involve and why you feel it may not be in their relative's best interests. It is also important to show sensitivity at what may be a distressing decision for family members.

Family members and friends may not take in all the information given to them in a once off discussion. It is therefore useful to revisit these conversations from time to time and see whether their views have changed after having thought over the issue or after seeing their relative's dementia progress.

## 6.4 Dealing with grief and loss

It is sometimes assumed that care home placement provides relief to overburdened family carers who can no longer maintain care at home. While this may be the case, it can also be an extremely distressing and difficult time for them (33). Family carers may be left feeling grief and shame about the decision and have unmet information needs about the care home system (34).

The course of dementia over many years and the gradual loss of the relationship and uncertain life expectancy make it difficult for families and carers. Grief is often felt before the death of a friend or relative with dementia and this grief has been described as the carer's response to the "perceived losses in a valued care recipient. Family caregivers experience a variety of emotions (e.g. sorrow, anger, yearning and acceptance) that can wax and wane over the course of a dementing disease, from diagnosis to the end of life." (p2203)(35). It occurs due to the lengthy and uncertain disease trajectory; compromised communication between the person with dementia and family and friends; and changes in relationship quality and carer freedom.(35) Higher grief prior to death is associated with complicated grief after death (36) so emotional support during care rather than solely after the death may be beneficial.(37)

Helping carers to prepare for end of life may help them adjust to and cope with their relative's death (38-40). Preparation for end of life has medical, psychosocial, spiritual and practical components, (41, 42) including knowing what to expect about the terminal condition

and having funeral plans in place.(43) Good communication with healthcare providers to discuss prognosis, treatments, cultural, spiritual and practical issues; and dealing with family conflict is important for helping carers feel more prepared (41).

Care homes and nursing homes have a number of options for providing emotional support and information to carers. Information could be provided in group or individual sessions. Peer support through carer support groups can be helpful as can annual memorial services for deceased residents.

## 6.5 Where to go for support and information for carers

If a family member is struggling with grief there are a number of national support lines available. Below are a list of organisations and their website and helpline telephone number. The organisations below also have information brochures and booklets about dementia, end-of-life care and grief support:

### Marie Curie

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Support Line: 0800 090 2309

### Alzheimer's Society (England, Wales and Northern Ireland)

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

National Dementia Helpline 0300 222 1122

### Alzheimer Scotland

<http://www.alzscot.org/>

24 Hour Dementia Helpline: 0808 808 3000

### Dementia UK (Admiral Nursing Service)

[www.dementiauk.org](http://www.dementiauk.org)

Dementia Helpline: 0800 888 6678

### Carers UK

[www.carersuk.org](http://www.carersuk.org)

Help and Advice Line: 0808 808 7777

### Cruse Bereavement Care

<http://www.cruse.org.uk/>

Helpline: 0808 808 1677

# APPENDICES

## Appendix 1: Compassion Holistic Assessment

### Option 1: Compassion Holistic Assessment Checklist

- ☐ Details of family/ important others involved in care decisions
- ☐ Lead clinician/GP details/Consultant details
- ☐ Level of meaningful communication & understanding
- ☐ Life story and interests
- ☐ Needs related to faith and/or culture
- ☐ Dementia diagnosis and severity
- ☐ Significant other medical conditions
- ☐ Recent change in condition
- ☐ Medications, recent changes in medications and why
- ☐ Presence of pain or discomfort: For example - Pain Assessment in Advanced Dementia [PAINAD] scale (21); A PAINAD score of 2 or more can be used as an indicator of probable pain. A score of 1 is a sign to be attentive to possible pain (22)
- ☐ Assessment of potential triggers to behavioural symptoms of dementia (including agitation, aggression, apathy, repetitive movements, disinhibition, sleep disturbance)
- ☐ Psychological wellbeing, mood, anxiety, hallucinations (visual) or delusions (auditory) or depression, e.g. Cornell Scale for Depression in Dementia (23)
- ☐ Mobility, falls risk, sitting balance and posture, contractures/tone
- ☐ Skin conditions, pressure ulcer risk (e.g. Waterlow Score Card available from: <http://www.judy-waterlow.co.uk/the-waterlow-score-card.htm>)
- ☐ Continence, constipation/bowel problems, UTIs
- ☐ Eating and swallowing, oral care, weight loss, nutritional status
- ☐ Record of end of life wishes, including preferred place of death and whether or not resuscitation is to be attempted

## Option 2: Compassion Holistic Assessment template

Name:		
DoB/ Age:		
Room number:		
Details of family/ important others involved in care decisions:		
ICL: Lead clinician: GP details: Consultant details:		
Dementia diagnosis and severity		
Life story, interests		
Significant other medical conditions:		
Current medication:		
Recent changes in medications and why		
Needs related to faith and/or culture:		
Record of end of life wishes:	DNAR: YES/NO Advanced Care Plan details and wishes:	
Date completed and signature		

	Problems/ needs identified:
Level of meaningful communication & understanding:	
Presence of pain or discomfort: (PAINAD score)	PAINAD at rest:                      PAINAD during movement:
Behavioural symptoms (BPSD) and/or sleep disturbance:	
Psychological wellbeing, mood, anxiety or depression:	
Mobility, falls risk, sitting balance and posture, contractures/tone:	
Skin conditions, pressure sore risk: (Waterlow score)	
Continence, constipation/bowel problems, UTIs:	
Eating and swallowing, oral care, weight loss, nutritional status:	
Other health problems	
Recent change in condition:	
Date completed and signature:	
Additional notes:	

## Appendix 2: Compassion Personal Care Plan

Name:		
DoB/ Age:		
NHS number:		
Important goals for care & wellbeing:		
Identified symptoms/ area of unmet need:	Action plan and goal, with review date:	
Areas of anticipated/ possible future need:	Action plan and goal:	
Date completed and signature:		



### Appendix 3: Compassion Personal Care Plan Review

Name: DoB/ Age: NHS number:		Date completed and signature:
Summary of actions and outcomes since last assessment		
Identified symptoms/ area of unmet need:	Revised action plan and goal, with review date:	
Details of review, changes since last assessment		

## Appendix 4: PAINAD (Observational pain scale)

Name:

Date completed:

### PAINAD 1: During Rest

INDICATOR	SCORE = 0	SCORE = 1	SCORE = 2	TOTAL
Breathing	Normal breathing	Occasional laboured breathing; Short period of hyperventilation	Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respiration	
Negative vocalisations	None	Occasional moan/groan. Low level, speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimace	
Body language	Relaxed	Tense, distressed, pacing, fidgeting	Rigid, fists clenched. Knees pulled up. Striking out. Pulling or pushing away	
Consolability	No need to console	Distracted by voice or touch	Unable to console, distract or reassure	
TOTAL: (Max 10)				

### PAINAD 2: During Movement

INDICATOR	SCORE = 0	SCORE = 1	SCORE = 2	TOTAL
Breathing	Normal breathing	Occasional laboured breathing; Short period of hyperventilation	Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respiration	
Negative vocalisations	None	Occasional moan/groan. Low level, speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimace	
Body language	Relaxed	Tense, distressed, pacing, fidgeting	Rigid, fists clenched. Knees pulled up. Striking out. Pulling or pushing away	
Consolability	No need to console	Distracted by voice or touch	Unable to console, distract or reassure	
TOTAL: (Max 10)				

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