

**Appendix A: Care at the End of Life Cameos**

## CAMEO 1

### ***Slowly, but Relentlessly Progressive Diseases***

**AB is a 35 years old woman with severe primary progressive multiple sclerosis (MS.)**

**She lives with two school-aged children, supported by elderly parents and a Local Authority funded Care package overseen by a Care Manager. Her swallow is worsening, her level of disability is increasing and she is no longer able to transfer without two people's assistance.**

**She develops a urinary tract infection (UTI) and is admitted to hospital.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p><i>She experiences uncontrolled pain and spasm whilst an inpatient that delays her discharge back home. The cause is complex.</i></p> <p><i>After 10 days, the admitting team seek assistance.</i></p>	<p>The Acute Trust had declined approaches for Palliative Care Sessions from the local Hospice, so only phone advice is available 'as a favour'. They suggest that the neurologist reviews her again (who visits only weekly). After another fortnight, her symptoms are tolerable,</p>	<p>She is referred to the hospital specialist palliative care team (SPCT), who control her symptoms within 48 hours.</p>
<p><i>She is discharged to a rehabilitation unit prior to her eventual discharge home.</i></p> <p><i>She is assessed</i></p>	<p>Referrals are made to relevant therapy services based on the needs that have emerged during her stay, but care is not very well co-ordinated</p>	<p>This episode is seen as a critical decision point and a full assessment occurs involving the therapies team, the community SPCT and Social Services.</p> <p>A care plan is drawn up as part of being placed on the <b><i>Palliative Care Register</i></b>. They agree to review specific issues as they arise.</p>
<p><i>Her follow up at home</i></p> <p><i>Her GP and the community nurses are the foundation of her network:</i></p>	<p>She is seen by relevant therapists in response to referrals by Primary Care.</p> <p>The Community SPCT does not feel that she merits specialist input, but are willing to consider referrals for specific symptomatic need.</p>	<p>She is followed up at home by the therapies team and SPCT, who currently have a low input but start working with the family.</p>

**Two months later, her swallow has continued to deteriorate, as has her speech, she has lost weight and is malnourished (albumin of <25).**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p><i>The community speech and language therapist feels that PEG feeding is necessary.</i></p>	<p>The GP refers her back to the Neurologist, who phones saying that it is clearly time for a PEG 'in her best interest' and that she will arrange admission to Gastro-enterology for assessment by their team.</p> <p>She is admitted and the PEG is inserted.</p>	<p>The SPCT facilitates a discussion around future care as she now has communication difficulties and tires easily.</p> <p>She declines the PEG feeding tube. This triggers work to think about what acute treatments she may want in future.</p> <p><b><i>The Palliative Care Register is updated with this information</i></b></p>

**Some weeks later, she becomes unwell again with another UTI and a very severe chest infection. She is again admitted to the acute hospital for intravenous antibiotics.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
-------------	--------------------------	----------------------

<p><i>She has difficulty expressing her choices: does she want</i></p> <ul style="list-style-type: none"> <li><i>Assisted ventilation to help treat her chest infection?</i></li> <li><i>the team to attempt CPR in the event of a cardio-respiratory arrest?</i></li> </ul> <p><i>Her symptoms also prove difficult to control on the general ward and her family are very anxious.</i></p>	<p>The admitting team feel worried about her capacity as much of her language is unintelligible and her mother says she doesn't want any acute treatments.</p> <p>The neurologist is on holiday, so she is referred to the psychiatrist to exclude depression and a decision is taken to ventilate and resuscitate should there be a sudden deterioration before she is seen.</p>	<p>The hospital SPC team transfer her into one of their beds for acute management of nausea and breathlessness and urgent decision-making support and assisted communication. Using their advanced skills she is able rapidly to think through these issues and concludes that</p> <ul style="list-style-type: none"> <li>She does not want artificial ventilation or CPR in the future.</li> <li>She is helped to formalise this in writing with a valid and specific advance refusal.</li> </ul> <p><b><i>The Palliative Care Register is updated with this information</i></b></p>
<p><b>One month after her discharge home, AB again develops an infection. The current care package is now inadequate as her dependency begins to increase rapidly and she needs constant care.</b></p>		
THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p>Something needs to be done</p>	<p>She is admitted to Hospital, and the same process is initiated. This time she is seen by the neurologist.</p> <p>She is desperate to go home as her children find visits distressing and don't cope well with the open ward environment.</p> <p>The hospital staff are very worried to be discharging her in her current state and want there to be a case conference to discuss her needs. It takes a fortnight to arrange.</p>	<p><b><i>The GP calls the 0800 End of Life Care Coordination Number.</i></b></p> <p>SPCT discuss the treatment options and explore whether, in the light of her advance directive, she wants admission to an acute hospital.</p> <p>She decides to remain at home with symptom management and psychosocial support to maximise quality time with her daughters.</p>
<p>Three weeks later</p>	<p>A protracted discussion now begins as to whether her care needs are to be funded by Social Services or Health. A fortnight later her needs are reassessed and her case is presented to a continuing care panel in her PCT. They agree that she now has continuing care needs and that all her care is to be funded by the NHS.</p>	<p>The SCPCT visit regularly and working with the GP, coordinate other home support services including social care, an occupational therapy home assessment for appropriate aids, a hospital bed, commode and increased hands on nursing care.</p>
<p><b>AB continues to deteriorate</b></p>		
THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p>One month later</p>	<p>She goes home with a new set of agency carers funded by the PCT.</p> <p>There are major communication problems with AB from both ends and the care package disintegrates because of this. AB's complaint is that the staff simply don't understand how to meet her needs.</p>	<p>The SCPCT help her to decide where she would like to die. Her preference is for home or hospice if home becomes impossible.</p> <p><b><i>This is an automatic, audited entitlement of being on the Palliative Care Register.</i></b></p>

	<p>After several changes in carers, the Community Nurses approach the Hospice to ask for a respite admission. They are able only to offer a bed in ten days.</p> <p>In the meantime, after several nights of no sleep, her parents cannot cope she develops worse symptoms in the night and is admitted to hospital at 2am pending the hospice place.</p>	<p>An effective collaboration has been negotiated locally as part of the End of Life Strategy for a partner agency to develop a team of staff interested in caring for the dying. These workers are given additional, accredited training and support from the local SPCT and Community Nurses.</p>
	<p>AB is transferred to the Hospice and feels very relieved to be in a place of safety. She deteriorates rapidly, but at least her children have open access to her and are able to stay overnight.</p> <p>The case triggers a discussion in the unit about the need for earlier involvement in cases like this. The community team said that they had not received a referral recently although they had given the odd piece of advice in the past. Apparently there had been 'no needs that merited specialist input'.</p> <p>The Hospice give bereavement support to the family.</p>	<p>She is looked after by her GP, DNs, and SCPCT, who also support the family and liaise with the children's school. For the last three days, there is a twenty four hours nurse/ carer present. She dies peacefully with her family present. The SPCT give bereavement support to the family for the next six months.</p>

## Cameo 2

### SLOWLY BUT RELENTLESSLY PROGRESSIVE DISEASE

#### Dying a 'prolonged death' from Dementia: Two case studies of good practice

Mary died comfortably at home at the age of 74 in the arms of her partner John. John is missing Mary terribly but he is getting emotional and practical support from the local hospice, he has told the bereavement councillor that he is comforted by the fact that Mary died at home where she wanted. When he talks about Mary's last months he tells of the little things they were able to share together and how the 'well oiled machine' of the NHS and Social care was always there when they were needed.

When John is asked why did it work?

"Compassion in how the news was broken and open and honest discussion around treatment and choices of care (**Communications Skills**). As Mary became more poorly the support they needed was there in advance (**Case Management**). There were lots of people from Doctors to Home Helps who made a real difference and they operated as a single team (**Coordination**).

"Everyone knew about Mary, when Mary needed to go to hospital the Ambulance and the hospital staff treated her appropriately and after some tests and a change in her medication she got home the next day (**Register, Transport, Discharge**).

Mary was never in distress or pain for very long because whenever John called for help it was there 'double quick' day or night (**Rapid Response**)".

Mr M began to have short-term memory problems shortly after he retired. He and his wife visited their GP who GP referred Mr M to the local memory clinic for a full assessment and diagnosis. The consultant geriatrician diagnosed early Alzheimer's disease and Mr M was referred to an **Alzheimer's Nurse Specialist/ Alzheimer's Society outreach worker (ANS/OW)**.

He explained to Mr and Mrs M about Alzheimer's disease and advised them about the support and services available, and offered to make referrals to local and national services as their needs changed.

Mr M's health and well being was monitored by the ANS/OW in partnership with Mr M's GP. After five years Mr M's condition had deteriorated and he became eligible for anti-dementia drugs. Mr and Mrs M had been speaking on and off together about the future, but found this difficult and distressing.

At his full review by the specialist clinic, it became apparent that this was the best time to discuss his future options and preferences. They agreed that it was wise to go onto the **Palliative Care Register** even though Mr M may well enjoy several more years of continued physical health. The ANS/OW, introduced Mr M and his wife to the **Charter of Entitlements**.

Together they worked to create a profile and life history document. With his wife and family Mr M agreed and made financial arrangements for the future, he completed a **Lasting Power of Attorney** and recorded the things that people caring for him in the future should know about him.

The ANS/OW agreed with the family the conditions under which the charter needed to be revisited and their decisions reviewed and when the local advocacy service could be involved. The ANS/OW made an introductory appointment with the service.

Three years later, when Mr M required more support the ANS/OW referred Mr M to social services who provided home care services and to a local Alzheimer's Society day care centre. Four years later, the ANS/OW supported Mr and Mrs M during his move to a long-term Care Home and with the registration of his Lasting Power of Attorney. The ANS/OW continued to visit Mr M and was available to advise the team caring for him.

**The Care Home, a Hospice Kite-marked Service**, were fully aware that Mr M did not want any invasive treatments or admission to hospital. On several occasions he had periods of confusion and transient weakness suggestive of small strokes. He had also needed antibiotics for chest infections as he had developed some difficulty swallowing. These were all managed by the care home. One weekend he had a stroke and in the subsequent week he became less rousable and died in his sleep. The ANS/OW remained in contact with Mrs M and was able to advise and support Mrs M and linked her into local bereavement services following her husband's death.

## Cameo 3

### PROGRESSIVE DISEASES PUNCTUATED BY SERIOUS OR LIFE-THREATENING EPISODES

**Mrs W, who suffered with both Chronic Obstructive Pulmonary Disease and Ischaemic Heart Disease heart for some years has had numerous admissions with acute breathlessness due either to her COPD or unstable angina and rhythm disturbances. She is beginning to wonder if she is nearing the end of the road.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p><i>However, she is now beginning to struggle with her breathlessness and heart failure and is effectively house bound. Clinic attendance leaves her exhausted for several days and she refuses to go.</i></p>	<p>The Heart Failure CNS (HFCNS), an Acute Trust employee, knows Mrs W well, but is forbidden from seeing patients at home because of risk management and indemnity.</p> <p>Mrs W's Community Matron (CM) therefore attempts to control her increasing breathlessness and anxiety using phone advice from HFCNS. The SPC Team says they don't have the skills to advise.</p> <p>Things continue to deteriorate and there is no option but to admit her.</p>	<p>Following publicity by the local advocacy service, for all over 65's, wanting to plan their future health care, Mrs W had heard that if her worry that she might die in the next year was founded, she could be placed on the Palliative Care Register.</p> <p>In a joint assessment by the CM and HFCNS at home, Mrs W brings this up.</p> <p>They all agree, using the Seattle Heart Failure Model<sup>1</sup> that links increased complexity of care to increased risk of mortality, that Mrs W needs more supportive care, and inclusion on the <b>Palliative Care Register</b>.</p> <p>They also make some drug changes and plan a 5 day admission using the standard protocol for palliative management. The HFCNS begins to discuss the kinds of treatment that will be considered and gives Mrs W leaflets to read in anticipation of the options she may wish to consider.</p>
<b>Mrs W is admitted for assessment</b>		
<p><i>There are several technical options for management including the insertion of a combined biventricular pacing wire and implantable defibrillator (ICD),</i></p>	<p>The usual admission for deteriorating failure is 7-10 days.</p> <p>Mrs W meets the criteria for pacing and ICD. The cardiologists explain that this will be a good thing as it will help the heartbeat and will stop any fatal changes in rhythm. No mention is made of the effects of repeated shocks from the ICD in a patient who is dying despite them. She is not told that it can be switched off if the sensations from internal defibrillations are distressing.</p> <p>Because of the time she was admitted that week, there were some delays before the procedure could be done</p> <p>There is some improvement in Mrs W's symptoms.</p>	<p>The standard admission for palliation coordinates trials of iv drugs, investigations and a pre-booked slot for any necessary invasive procedures like pacing/ICD placement.</p> <p>Mrs W is worried that the wires may be more trouble than benefit. She is reassured to hear that they can be switched off at any time if she wants that or if they cause her distress.</p> <p>She agrees to this, but 'wants it in writing'.</p> <p>The CM and HFCNS help her make an <b>Advanced Statement</b> expressing</p> <ul style="list-style-type: none"> <li>• Her treatment preferences,</li> <li>• that she does not want any further admission to hospital if at all</li> </ul>

<sup>1</sup> <http://SeattleHeartFailureModel.org>

	THE ADMISSION LASTS 14 DAYS	possible This is an automatic, audited entitlement of being on the Palliative Care Register, which is updated with this information <b>THE ADMISSION LASTS 5 DAYS</b>
<b>Mrs W goes home and the next three months are relatively trouble free</b>		
<b>THE PROBLEM</b>	<b>CURRENT TYPICAL PRACTICE</b>	<b>GOOD FUTURE PRACTICE</b>
	<p>The CM takes the role of coordinator by default and tries to arrange an MDT meeting. She ends up responding to need piecemeal, as it isn't possible to get everyone together.</p> <p>Mrs W knows how difficult it is and is very grateful for all her effort. She tries not to be troublesome and only calls when absolutely necessary.</p> <p>The CM makes a referral to SPC in the hope that they can do some emotional and family work. They are rather reticent as there is no-one confident in looking after heart failure, but they will arrange a training day and get back to her. In the meantime, their consultant will be happy to do single assessments if that is of help. It is not. It's the family and inappropriate admissions that worry her.</p>	<p>To implement her preferences, A multidisciplinary team meeting was arranged; the Community Matron was designated as main contact, responsible for ensuring information about the patient was passed on, and as the person to ensure that the patient and her family were made aware of the worsening situation and given the <b>0800 number for patients on the Register.</b></p> <p>The GP and CM worked with the patient and family to provide an anticipatory care package.</p> <p>The Community SPC Team has been notified about Mrs W at their monthly review with the HFCNS of potential acute problems. The CNS' have each developed areas of interest, and he arranges a tutorial for the rest of the team to anticipate any on call issue that may arise.</p> <p><b><i>The Palliative Care Register is updated with this information</i></b></p>
<b>Mrs W's general condition begins to deteriorate, but one weekend she complains of episodes of thumping and tightness in her chest that come on with dizzy spells. She reports it as being as bad as the heart attacks, but short lived and unpredictable.</b>		
<b>THE PROBLEM</b>	<b>CURRENT TYPICAL PRACTICE</b>	<b>GOOD FUTURE PRACTICE</b>
<i>The defibrillator is triggering.</i>	<p>She is admitted via casualty as she is very frightened. The on call doctor reassures her that this is the ICD 'doing its job' and that she needs to relax and get accustomed to the feeling. Her breathlessness is bad from anxiety. She says she wants the ICD switched off. They elect to keep her in for review by cardiology in the week.</p> <p>She is seen and every effort is made to change her mind. She is adamant that she would rather 'take her chances' than have the attacks from the ICD. They agree to switch it off, but she is required by hospital policy to sign that she is stopping life prolonging treatment against specialist advice and that she may die as a result.</p> <p><b>THE ADMISSION LASTS 5 DAYS</b></p>	<p><b>The family call the End of Life Care 0800 number.</b> SPC visit and reassure Mrs W that it is the ICD. She is given some additional sedation and settles.</p> <p>She is very upset: 'I had no idea it would do this to me'</p> <p>There is no need for admission, but she needs a review in the week.</p> <p>The HFCNS visits with the Cardiologist who discusses the implications of Mrs W's wish. He is satisfied that she is making an informed refusal and deactivates the ICD.</p> <p><b>The CM helps Mrs W's revise her Advanced Statement,</b> which now states that</p> <ul style="list-style-type: none"> <li>• she no longer wishes admission at all and</li> <li>• does not want resuscitation or life</li> </ul>

		<p>saving treatment,</p> <p><b><i>The Palliative Care Register is updated with this information</i></b></p> <p><b>THERE IS NO NEED FOR ADMISSION</b></p>
<p><b>Three weeks later, Mrs W developed chest pain and became distressed.</b></p>		
<b>THE PROBLEM</b>	<b>CURRENT TYPICAL PRACTICE</b>	<b>GOOD FUTURE PRACTICE</b>
<p><i>A friend who was visiting, not aware of Mrs W's wish to stay at home, called the ambulance.</i></p>	<p>The Ambulance Crew were expecting a 'cardiac case' and arrived with O<sub>2</sub> and the resuscitation pack.</p>	<p>The <b>automated alert at Ambulance Control</b> linked to Mrs W's name, date of birth and address, showed that Mrs W was on the <b>Palliative Care Register</b> and the paramedics were aware of this and the details of her advanced care plan to stay at home.</p>
<p><b>They find Mrs W pale, sweaty and in pain.</b></p>		
<b>THE PROBLEM</b>	<b>CURRENT TYPICAL PRACTICE</b>	<b>GOOD FUTURE PRACTICE</b>
<p>The Ambulance Crew arrived,</p>	<p>They treated Mrs W's acutely with analgesia and oxygen and a line inserted.</p> <p>Mrs W said she didn't want to go to hospital, but the crew said that they really couldn't leave her in this state as the portable monitor was showing that she had probably had a heart attack, and it was best to be checked in casualty. 'She could always come home if things settled'.</p>	<p>They treated Mrs W's acutely with analgesia and oxygen</p> <p>Having confirmed that she was the person referred to on the register and that she did not want admission, they stayed whilst her symptoms settled and the Community Nurse arrived.</p> <p>Oxygen and drugs were already available in the house for the Out of Hours GP to prescribe.</p> <p><b><i>The Palliative Care Register is updated with this information</i></b></p>
<p>The family arrived</p>	<p>They agreed that, since the ambulance was already here and mum was obviously not being herself, that a brief stay in hospital was the best plan since there was no O<sub>2</sub> or strong analgesia in the house</p>	<p>The family were able subsequently to speak to the 0800 support line at any time for reassurance and advice.</p>
	<p>Admission,</p>	<p>Mrs W died peacefully in her sleep that night, her symptoms controlled, with her family at her bedside. The local advocacy service, when informed of her death by her CM, arranged access to bereavement care for the family.</p> <p><b><i>The Palliative Care Register is updated with this information</i></b></p>
	<p><b>20 DAYS IN HOSPITAL</b></p>	<p><b>5 DAYS IN HOSPITAL</b></p>

## CAMEO 4: Unexpected and Acute Death

**Mr H, a 58 year old man, collapsed unconscious at work late one afternoon and was taken to his local A&E department. An emergency MRI showed a catastrophic cerebral bleed. Vital structures had been compromised.**

THE PROBLEM	THE WORST CURRENT PRACTICE See End of Life Care, 2007, 1:88-90	GOOD FUTURE PRACTICE
<p><i>Mr H was transferred to the stroke assessment unit and was not for any active treatment.</i></p> <p><i>His wife, a senior nurse, was abroad; His children were travelling from either end of the country.</i></p> <p><i>The question concerning the doctors was whether he should be resuscitated.</i></p>	<p>Nurses were scarce, overworked, distracted and cold. The majority were agency staff.</p> <p>Designated, routine tasks took priority over nursing care.</p> <p>His wife rang from Europe, but giving information over the phone was against policy, All she learned was that his life was 'in no more danger than anyone else on this unit';</p> <p>When she informed the nurse that whilst she would not fly in until the next day, her children were on their way, they responded curtly that there was no open visiting policy</p> <p>On arrival Mr H's children were distraught. Whilst very supportive and open, the junior doctors had required them to agree that a DNAR was appropriate. Later they were to say that they really had no idea what they were or were not agreeing to.</p> <p>When Mrs H arrived the next day, the doctors contrasted strongly with the nurses in their empathy and openness. The MRI showed the inevitable fatality of the intracerebral bleed.</p> <p>The doctors gave reassurances that Mr H's symptoms would be controlled.</p>	<p>There is a unit policy on how to handle unexpected, catastrophic strokes</p> <p>Every effort is made to contact family;</p> <p>Where possible, the patient is in a single room;</p> <p>There is open access to immediate family;</p> <p>The senior nurse takes responsibility for initial news breaking, but the on call consultant takes responsibility for detailed discussion over DNAR orders and gaining consent for acute interventions.</p> <p>The nursing staff explained to Mrs H the urgent need to get back and took her mobile number. The on-call consultant would ring her back once he had all the facts.</p> <p>He spoke with the children, and then with Mrs H in their presence, saying that they would discuss matters in detail the following day, but that the team would make every effort on Mr H's behalf He said that were Mr H to arrest it would be extremely unlikely that they would be able to resuscitate him. However, whilst he would not advise it, should she wish, they would take all reasonable steps to keep him alive pending her arrival.</p> <p>Mr H was started on the <b>Liverpool Care Pathway</b></p>

**Mr H's condition deteriorated overnight. He appeared agitated, had vomited some 'coffee grounds'. A source of pain could not be excluded, given his raised intracranial pressure and probable gastritis. He was not clearing his chest secretions either**

THE PROBLEM	THE WORST CURRENT PRACTICE	GOOD FUTURE PRACTICE
<p><i>Mrs H had arrived</i></p> <p><i>Mr H needed acute symptom control.</i></p> <p><i>He had a urinary catheter, cardiac monitoring and a nasopharyngeal airway to protect his airway and allow suction.</i></p>	<p>No physical nursing care or monitoring had occurred for over 6 hours despite mouth breathing and his agitation and abdominal pain.</p> <p>He was only scripted for paracetamol The nurses refused diamorphine for fear of suppressed respiration.</p> <p>Mrs H demanded that Palliative Care be called. He was comfortable within</p>	<p>Mr H had received single injections of anti-emetic and a small dose of diamorphine overnight. At handover they had left an ansafone message and faxed a referral to the hospital palliative care team for symptom control and psychological support.</p> <p>The palliative care specialist (Consultant Nurse) arrived on the ward at 9am Together with the ward staff, he ex-</p>

	<p>the hour and they sat with the family until everything settled.</p> <p>A syringe driver regime was recommended. The team are not permitted to write on other consultants' charts without permission. It was never started.</p> <p>Mrs H asked for a side room, but none was available. It was 'full of the physiotherapy department's rubbish'</p>	<p>plained that he probably beginning to die. They talked through the process that was likely to unfold, the importance and safety of symptom control and the support that they would receive.</p> <p>The on call consultant joined the palliative care specialist, and they agreed a management plan, that resuscitation was futile and removed the monitors. Since there was no single room available, they offered to move Mr H to their ward.</p>
	<p>He continued only to receive direct nursing care when it was requested by the family. On one occasion the family was criticised for asking that Mr H be turned as the senior nurse claimed that it had led to further bleeding, soiled linen and distress. The necessary care had interrupted the medicine's round</p> <p>Mr H died in distress later that day. The family were left to turn off the cardiac monitor themselves. The extent of the post death support was a leaflet as they left the ward.</p> <p>A formal complaint, handled well by managers, has led to significant changes.</p>	<p>A subcutaneous syringe driver was commenced containing some analgesia, an anti-emetic and an anti-secretory agent.</p> <p>It was not necessary to suction Mr H again as the secretions were controlled.</p> <p>He died comfortably 36 hours later.</p>

## Cameo 5

### THE END OF LIFE: Fading Away - THE NEED FOR PLANNING

Mr B, who is 74, lives in a care home and has incurable stomach cancer. As far as the hospital is concerned, there is nothing more that can be done, but he remains on a number of drugs. Given his disease, he looks in remarkably good health. Over about 10 days, he spends more time in bed and by the end of the weekend he has stopped eating despite coaxing from the staff and is most reluctant to take his medication.

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p><i>What should be done for Mr B?</i></p>	<p>They are concerned and call the GP.</p> <p>They also make a referral to palliative care.</p> <p>A Palliative Care Nurse Specialist does a joint visit with the GP.</p>	<p>At the time of diagnosis, when Mr B heard of his disease, he elected not to have treatment. He was referred to palliative Care in the Hospital and was put on the <b>Palliative Care Register</b> . As part of a full End of Life Assessment,</p> <ul style="list-style-type: none"> <li>• He discusses his <b>Preferred Place of Care</b>;</li> <li>• As part of his <b>Advanced Care Planning</b>, He discusses scenarios that may occur and feels that he does not want to be admitted to hospital unless there was a clearly reversible problem unrelated to his cancer.</li> <li>• He stated that he hoped just 'to fade away', wants to be in 'his own bed' (this is in the Care Home in which he has lived since his wife died).</li> </ul> <p><b>The Palliative Care Register is updated with this information</b></p>
<p><i>Care Planning:</i></p> <ol style="list-style-type: none"> <li>1. <i>Is Mr B to be admitted anywhere?</i></li> <li>2. <i>What is to be done about symptom control?</i></li> <li>3. <i>What is to be done about food and fluids?</i></li> </ol>	<p>There has been none, despite the fact that his cancer is documented as being incurable</p> <ol style="list-style-type: none"> <li>1. Both agree that Mr B is probably dying. No one knows where he wants to be to die. They try and talk to him, but he turns his face to the wall, although on being pressed, he says he is comfortable, not thirsty and wants just to be left alone.</li> <li>2. However, the GP refuses to stop any oral medication or take any decisions without discussion with his Oncologist. The oncologist is not available until Monday. Mr B takes oral painkillers when necessary. The GP resolutely refuses to script injectable opioids or sedation without ratification by oncology. When challenged, she says that there is no indication and she was</li> </ol>	<p>Like all Care Homes in the area, there is a <b>Monthly Gold Standards Framework Meeting</b>. Several GPs work with the home and only attend these meetings if relevant. Mr B is discussed automatically, being on the <b>Palliative Care Register</b>.</p> <p>There is an intuition amongst the staff that he may be ailing. The GP and the Palliative Care CNS have checked on him at each meeting and agree. They have been careful to ensure that Mr B hasn't changed his mind about care etc.</p> <p><b>The Palliative Care Register was regularly updated with this information.</b></p> <p>Mr B's current deterioration isn't a surprise and his <b>Advanced Care Planning and Preferred Place of Care</b> is both known and documented.</p>

	<p>not a 'Shipman'.</p> <p>3. The GP also instructs that if the staff cannot get Mr B to drink, he is to be sent to casualty for management. "Two of my patients have died here over the last year and I'm not prepared to risk awkward questions. That happened to a colleague recently</p>	<ol style="list-style-type: none"> <li>1. Mr B is therefore not to be admitted to hospital;</li> <li>2. At the joint assessment by the CNS &amp; GP, they ensure that the medication necessary for symptom control is in place. However, they both agree that he is not yet ready to go onto the <b>Liverpool Care Pathway</b>, although the Home's staff may revise this with the Community Nurses over the weekend.</li> <li>3. Mr B should be encouraged, but not forced, to drink and to have his routine medication.</li> </ol>
<p><b>Predictably, Mr B refuses to eat and drink and becomes quite aggressive with the nurses who try to feed him. His mouth is dry and he is not passing urine. The staff speak to the care home manager.</b></p>		
THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p>Is Mr B to be admitted anywhere?</p>	<p>There is no arrangement for deputizing on call services to the care home unless a GP offers it personally. Palliative care support is only by phone.</p> <p>The Care Home's Company has a policy that all patients who deteriorate unexpectedly must be seen by the GP or sent to casualty.</p> <p>Mr B is sent to A&amp;E</p>	<p>The Community Nurses are visiting daily, and whilst Mr B is taking sips, the team in consultation with the GP and CNS feel that on balance, he should start on the <b>Liverpool Care Pathway</b> overseen by the Community Nurses.</p> <p>He is comfortable, but <b>Palliative Care will visit on call</b> if necessary.</p> <p>Over the next few days, he stops drinking entirely and spends more time asleep. As a precaution, his oral morphine and anti-emetic is converted to injectable doses and a syringe driver is started.</p>
<p>Over the next week</p>	<p>Mr B was admitted to the local hospital rather than his cancer centre No notes are available and he is therefore treated as a man with the reversible consequences of dehydration.</p> <p>He is found also to be anaemic and is given blood. His objections to interference are taken to be confusion secondary to the assumed acute problem.</p>	<p>He needs no other intervention other than good nursing care. The Care Home team is supplemented by trained carers from the <b>Rapid Response Team and Marie Curie nurses overnight</b>. The night community nurses check by phone each evening, but no visits are necessary.</p>
	<p><b>7 DAYS IN HOSPITAL</b></p>	<p><b>NO DAYS IN HOSPITAL</b></p>

## Cameo 6

### WE TOOK HIM HOME TO DIE - THE PROBLEM OF PROLONGED DEATH

Mr A a fiercely independent widower of 85 and has been losing weight for some months. He managed to hide it from his family, but was confronted when he became jaundiced. His daughter took him to the GP who admitted him immediately. Three weeks investigation discovered a disseminated adenocarcinoma, primary unknown. He refused all treatment and he continued to deteriorate rapidly. The oncologist believes that he has only a couple of weeks to live.

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p><i>Mr A knows that he is dying and demands to go home.</i></p>	<p>He is unable to care for himself, but one of his granddaughters, Tracy, agrees to move in 'seeing as he's only got days left'. She says she can manage and "anyway, he won't have any strangers in."</p> <p>The community nurses (DNs) provide support. The GP is asked to visit fortnightly to avoid the need for a coroner referral at death.</p> <p>There are no complex pain or symptoms, so he is not referred to SPC.</p>	<p>As a routine part of <b>Advance Care Planning</b>, it was clear that Mr A wanted to die at home. He was introduced to the Inpatient arm of the <b>integrated palliative Care Service</b> during which time the need for significant support for Tracy was explained and agreed. He understood that to have any chance of staying at home, he would need to agree to carers visiting. He also met the community Clinical Nurse Specialist (CNS) as part of his discharge planning. Mr A also agreed for the CNS to liaise directly with his GP practice, who had known the family for many years. The <b>GP practice was a GSF practice</b> and Mr. A was put on the <b>GSF register</b>.</p>
<p>Mr A is extremely cantankerous and abusive to the DN's who visit. They remember him from a few years ago when his wife was dying.</p> <p>Over the next fortnight his weakness limits him to bed.</p>	<p>Tracy said he was always like this and he has always been the boss.</p> <p>The DN's only continue to visit because he is getting weaker with episodes of confusion and they wish to support Tracy.</p> <p>The impression is that he will need a syringe driver soon.</p>	<p>In discussion with Mr A, Tracy, the Community Matron (CM), the GP and the community CNS a care plan was agreed that involved regular visits for support. Team members are all aware of Mr A's manner, his secrecy and suspiciousness and the likely difficulties that this will lead to. The standard approach is for the key worker to develop relationship with the patient urgently. It was agreed in this case that it should be the CNS, given that time was short and that specialist assessment and communication skills would be needed. Accordingly, the Community CNS was quick to begin getting Mr A's life story.</p> <p>He began, after a couple of visits to talk about the war and told increasingly shocking stories of what he had seen. On questioning about how he coped, he said "That's when my faith ran out. There is no God – you just look after number 1".</p> <p>The CNS' intuitions were that this man would find it very hard to let go of the control he was exerting over his life and that his dying was likely to be difficult. There was much he needed to talk about and that he was certainly not ready to die yet.</p> <p>Aware of his own limitations and the rapport he was developing with Mr A, the CNS arranged some urgent supervision sessions with the psycho-oncology team to support the work he was doing.</p> <p>He also ensured that he liaised with the DN team twice a week to offer ongoing support to them. They were providing excellent support to Tracy</p>

		<p>but felt deeply for her.</p> <p>The CNS and CM fixed an early practice meeting with the GP to discuss the challenges of managing what was likely to be a “prolonged death”.</p>
--	--	--

**Mr A has taken to his bed, but is becoming increasingly agitated. He is only drinking sporadically. He refuses categorically to move from his flat.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p>Tracy is only just managing. She is being woken at night now and has had to deal with several episodes of incontinence.</p>	<p>The community nurses manage to arrange some night support from Marie Curie, but the PCT only has a budget for 3 nights per week. She has no daytime support.</p> <p>He refused a catheter.</p> <p>The local hospice team assess Mr A and advise on medication and a syringe driver regime should he need it.</p> <p>He refuses a hospice bed saying “<i>you only come out of there feet first</i>”.</p>	<p>It was clear that Tracy would need practical support and a chance to get out.</p> <p>The CNS and the DNs had been working with Tracy and Mr A in anticipation, and the Hospice at home manager had visited.</p> <p>Mr A had started to trust the CNS, so the support was gradually increased using a mixture of Marie Curie and Hospice at Home resource to give Tracy sleep at night. The DN visits also increased to 3x a day.</p>

**The incontinence and agitation worsened as he became semi-conscious He occasionally took sips of water. Tracy manages for another 10 days, It is now a month since Mr A was discharged home to die. Everyone is surprised that he is still alive. It is Saturday morning and Mr. A’s son arrives for the weekend.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
<p>Tracy is exhausted and losing faith. Other family members are now insisting that something is done.</p> <p>Mr A’s son has cornered the community nurse and is becoming quite aggressive “Either put him in somewhere or someone should put him out of his suffering.”</p>	<p>The community nurse fears for Mr A’s safety and has found the interaction with Mr. A’s son distressing. She rings the Hospice.</p> <p>They do not admit out of hours, but given the circumstances the consultant makes an exception and admits Mr A.</p>	<p>The DN contacts the on call palliative care CNS. Whilst it is not the regular CNS on call, she has had a full handover and visits urgently to talk to Mr. A’s son. Despite the support, the family are finding it difficult coping with the time that is taking for Mr A to die.</p> <p>The on-call CNS explains that on occasion patients are waiting for an event, a date or a visit from someone. The family are not aware of anything like this. The CNS also explained that he may simply be taking time preparing for death. She gave some indication that Mr A had a lot of unresolved issues hanging over from the war, but didn’t go into detail.</p> <p>Together with the <b>Hospice At Home Service</b> The CNS and DN are able to arrange 48 hours of continuous care at home for Mr. A. Tracy goes home for a couple of days. She returns having had some rest, determined to see it through.</p>

**Mr A is clearly dying. He needs terminal care.**

THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
-------------	--------------------------	----------------------

<p>Mr A is agitated, and disorientated. He can't swallow medication, is bedbound, semi-conscious and only tolerating small sips of water.</p>	<p>He had not objected to admission. He meets the criteria for the <b><i>Liverpool Care Pathway</i></b>.</p> <p>As part of the assessment it appears that Mr A is Catholic, but the family insist that he does not receive any chaplaincy at all since he "lost his faith after the war."</p>	<p>He is started on the <b><i>Liverpool Care Pathway</i></b>.</p>
<p><b>Mr A settles relatively quickly with the right medication, and the staff begin to work with the family. They were expecting him to die in the next few days. Apparently Mr A had been an exceptionally difficult man, but there seemed little indication of what lay behind this.</b></p> <p><b>The next week was quiet, and Mr A responded very little. Without any change in his medication or care, Mr A began to wake over about 24 hours and started asking for drinks. To everyone's astonishment, he also asked to see the priest. He asked for confession and the sacraments.</b></p>		
THE PROBLEM	CURRENT TYPICAL PRACTICE	GOOD FUTURE PRACTICE
	<p>The priest said that the details were of course confidential, but that Mr A had made his peace with God over matters concerning the war.</p>	<p>In the confidential team debriefing after the case, the CNS disclosed that Mr A had told the story that he had been given charge of some Japanese POWs to take them back to base. In the jungle, he confessed that the guards had shot them and reported them as killed whilst trying to escape.</p>
<p><b>Mr A died peacefully on the morning of 16 August, the day after VJ Day.</b></p>		