**SPAR**

**SUPPORTIVE AND PALLIATIVE ACTION REGISTER – CHANGING NEEDS IN PALLIATIVE CARE**

**INTRODUCTION**

Palliative care is care that improves the quality of life for residents/patients and their families facing the problems associated with life-limiting illness. It focuses on the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain, other physical symptoms and any additional problems including psychosocial and spiritual concerns.

**Anticipatory Care Planning (ACP)**

As you will be aware a very important part of all care is to think ahead to what is likely to happen and what might happen. This is described as Advance or Anticipatory Care Planning. This is particularly important when people need more support as they begin to fail and start to approach the end of their life. In turn this helps professional carers prioritise their time as they are more aware of whom they need to be concerned about and also who, to a certain extent, may need less of their time.

**Why Recognising Change Matters**

The key to developing a meaningful ACP is to recognise which of your residents/patients are beginning to fail and thus have increasing care needs. It may be that the recognition that a resident is failing alerts you to that person’s increasing needs or it may be the other way around and the recognition that someone’s care needs are greater alerts you to the fact that they are beginning to approach the end of their life. The speeds with which these changes occur are frequently very important. Someone who seems to be failing very slowly is likely to continue to do so whereas someone whose care needs are increasing daily is likely to continue to deteriorate rapidly. This failing rate and changing need can in turn suggest to some extent how long you might expect the person to live for.

**Approaching the End of Life/ Diagnosing ‘Dying’ -**

As a person fails and begins to approach the end of their life there are a number of care issues that should be considered. Knowing the resident’s and their family’s wishes is extremely helpful in making sure that the care at this time is appropriate for the individual. There is a need to make sure that the other Health Care Professionals involved are aware of the person’s changing need e.g. the GP, the Community Nurse and the Out of Hours Services. Professional carers should consider what might happen as well as what is likely to happen and plan accordingly. One important matter to consider is the most appropriate place for the continued care of the resident and in particular whether the resident’s care needs can best be met in the Care Home rather than in Hospital. It is also vital that the resident and their family are as aware as is practical of the deterioration and indeed the possible closeness of death.

It is attention to matters such as these that makes up a good Anticipatory Care Plan.

**Levels of Supportive and Palliative Need**

We would suggest that you divide your residents into three broad categories:

* **Rate of deterioration nil/minimal – ‘Green’** – Those who do not appear to be failing or who are failing very slowly, whose needs do not appear to be changing and who hardly seem any different over a number of months. In this situation it is likely that the resident’s life expectancy can probably be estimated in a large number of months if not years. This group’s requirement for supportive and palliative care is fairly small.
* **Rate of deterioration moderate – ‘Amber’** – Those who are noticeably failing and whose care needs are increasing but in a fairly slow manner, perhaps over a few weeks to a month. It may be that you might expect a resident in this category to survive for a few months (e.g. 3 -6 months). This group’s supportive and palliative care needs should be assessed.
* **Rate of deterioration rapid/major – ‘Red’** – Those who are failing quickly, whose care needs are increasing equally quickly and who are thus deteriorating rapidly. In this situation death might be anticipated in just a few weeks (or even a few days). This group have a high level of need for supportive and palliative care.

The most important point is that there is evidence of **changing need** as a result of **irreversible deterioration**.

**HOW TO DO THIS**

**Overview**

There are four aspects that are worth considering

* What disease/condition the resident has
* Their current wellbeing and what they are able to do
* How quickly they are deteriorating
* The ‘Surprise question’

**Disease / Condition**

The first thing to consider is what disease or diseases does the person suffer from.

As all professional carers have seen, some diseases can lead to death very quickly (e.g. widespread cancer), some have a slower but still quite clear deterioration (e.g. chronic lung disease) whilst other conditions seem to go on for ever (e.g. dementia).

**Wellbeing / Ability**

What the resident is able to do, their functional status, has been shown to have a significant bearing on their predicted survival.

Several scales have been developed to categorise people according to their level of need and this in turn can help to predict how long they might be expected to live for. One such scale is the Palliative Performance Scale v2.

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| PALLIATIVE PERFORMANCE SCALE (PPSv2) | | | | | |
| % | Ambulation | Activity / evidence of disease | Self care | Intake | Level of consciousness |
| 100 | Full | Normal activity  No evidence of disease | Full | Normal | Full |
| 90 | Full | Normal activity  Some evidence of disease | Full | Normal | Full |
| 80 | Full | Normal activity with effort  Some evidence of disease | Full | Normal or reduced | Full |
| 70 | Reduced | Unable to do normal job/work  Some evidence of disease | Full | Normal or reduced | Full |
| 60 | Reduced | Unable to do hobby/house work  Significant disease | Occasional assistance necessary | Normal or reduced | Full or confusion |
| 50 | Mainly sit/lie | Unable to do any work  Extensive disease | Considerable assistance required | Normal or reduced | Full or confusion |
| 40 | Mainly in bed | As above | Mainly assistance | Normal or reduced | Full or drowsy or confusion |
| 30 | Totally bed bound | As above | Total care | Reduced | Full or drowsy or confusion |
| 20 | As above | As above | Total care | Minimal sips | Full or drowsy or confusion |
| 10 | As above | As above | Total care | Mouth care only | Drowsy or coma |
| 0 | Death | - | - | - | - |

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All of the aspects in the PPSv2 should be easy to assess by staff working in a care home.

PPSv2 rating has been shown to be quite accurate in people dying with cancer e.g. a study has shown that only about 10% of people with a score of 50% or below would be likely to survive for more than 6 months. However the majority of patients/residents looked after in care homes are not dying of cancer and may well have a very low PPSv2 and yet live for many months. To be useful in the care home population the person’s level of need must be linked to the speed of their decline.

**Speed of Deterioration / How Quickly a Resident is Failing**

By and large if patients/residents seem to be failing quite quickly then the decline is likely to continue at that pace whereas a slow decline continues quite slowly – rapid changes tend to continue rapidly and slow changes tend to continue slowly. All care home staff will know residents who have required virtually total care for many months e.g. a resident who had a severe and disabling stroke several years previously. You will also remember frail residents who suddenly go downhill, deteriorate on an almost daily basis and die within a very few days e.g. a pneumonia in someone suffering with dementia. In the second example it is the **speed of change** that ‘rings the alarm bells’.

**Stabilisation**

In categorising your residents/patients what is important is speed of change. If someone’s deterioration is moderate then they would be in the ‘amber’ category. If they then stabilise and their deterioration is minimal they would move back to ‘green’ even if there care needs remained high. SPAR is about recognising **change in need** rather than need.

**The Surprise Question**

Another matter to consider is quite simply the ‘feeling’ that the various people involved in the care of the resident have about that persons approximate length of survival. This is often referred to as the ‘surprise question’ – e.g. ‘Would you be surprised if the person was to die within the next six months?’. Though this might seem slightly casual it can be quite helpful as it encourages consideration of possible death. It is also something that everyone can attempt.

**Team Involvement**

As with all important clinical matters it is important that as many of the professional care team as possible are involved in assessing the patients changing needs and likely survival time – all the care home staff have a significant role in this process.

**Guidance at End of Life (GaEL)**

Finally, mention should be made of the need for continued patient centred care in the last stages of life. NHSGGC have developed guidance for staff caring for people as they approach the end of life. This guidance follows the principles set out by the Scottish Government in 2013.

Further discussion around the use of GaEL is beyond the scope of this project. However, SPAR can assist identification of deterioration that will ultimately result in the use of GaEL.

**Summation**

Using your knowledge of how different conditions usually progress, combined with an assessment of the resident’s needs and an awareness of how rapidly the resident is failing should ensure that the supportive and palliative care needs of each resident is assessed. This raised awareness then allows these needs to be addressed.

**PROCESS**

**Initial Categorisation**

* Review all residents/patients considering
  + Their functional condition
  + Their rate of change/how quickly they appear to be failing
  + The ‘surprise question’
* Discuss with all staff involved with the residents care
* Assign them to one of the three categories
  + Green – those whose condition and their need for palliative care is not changing – may also be expected to live for six months or more
  + Amber – those whose condition is deteriorating (probably due to irreversible causes) and whose need for palliative care is clearly changing – may be expected to live for a few months
  + Red – those who have had sustained irreversible decline or sudden severe irreversible decline – may be expected to live for a few weeks
* Code their care plan records green, amber or red

**What to do next**

* Green – rate of deterioration nil/minimal
  + Consider commencing /updating Anticipatory Care Plan
  + Consider use of ‘My Thinking Ahead & Making Plans’
  + Consider GP use of Key Information Summary (KIS)
  + Review every month or if any significant or sudden change
* Amber – rate of deterioration moderate
  + Discuss deterioration with resident/patient and family. Share uncertainty
  + Agree plans for management/care of resident/patient and family if:
    - Improves
    - Maintains current functional status
    - Continues to deteriorate
  + Discuss with resident/patient’s Community Nurse and/or GP
  + Possible joint Care Worker & Community Nurse assessment
  + Consider preferred priorities of care informed by resident/patient and family wishes
  + Commence/update Anticipatory Care Plan
  + Consider use of ‘My Thinking Ahead & Making Plans’
  + Discuss with GP practice completion of DNACPR
  + Commence/update KIS
  + Revise Supportive and Palliative Action Register (SPAR)
  + Review weekly or sooner if sudden deterioration
* Red – rate of deterioration rapid/major
  + Discuss deterioration with resident/patient and family. Share uncertainty.
  + Prepare for possibility of imminent death/recovery
  + Agree plans for management/care of resident/patient and family if:
    - Improves
    - Maintains current functional status
    - Continues to deteriorate
    - Dies
  + Discuss with resident/patient’s Community Nurse and/or GP
  + GP review
  + Consider preferred priorities of care informed by resident/patient and family wishes
  + Consider anticipatory prescribing (Just in Case)
  + Update Anticipatory Care Plan
  + Discussion with GP completion of DNACPR and RNVoED
  + Update KIS (GP)
  + Consider need for NHSGGC Guidance at End of Life (GaEL)
  + Review daily or sooner if sudden deterioration
  + Revise Supportive and Palliative Action Register (SPAR)