Appendix A: Decision-Support Tool for NHS Continuing Healthcare

1. Behaviour: Human behaviour is complex, hard to categorise, and may be difficult to manage. Challenging behaviour in this domain includes but is not limited to:

- Aggression, violence or passive non-aggressive behaviour
- severe disinhibition
- intractable noisiness or restlessness
- resistance to necessary care and treatment (this may therefore include non-concordance and non-compliance, but see note below)
- severe fluctuations in mental state
- extreme frustration associated with communication difficulties
- inappropriate interference with others.

A specialist assessment of an individual with serious behavioural issues will usually be required which includes an overall assessment of the risk(s) **to themselves, others or property** with specific attention to aggression, self-harm and self-neglect and any other behaviour(s).

2.

Description	Level of Need
No evidence of "challenging" behaviour.	No Needs
Some incidents of "challenging" behaviour. A risk assessment indicates that the behaviour does not pose a risk to self or others or a barrier to intervention. The person is compliant with all aspects of their care.	Low
"Challenging" behaviour that follows a predictable pattern. The risk assessment indicates a pattern of behaviour that can be managed by skilled carers or care workers who are able to maintain a level of behaviour that does not pose a risk to self or others. The person is nearly always compliant with care.	**Moderate**
"Challenging" behaviour that poses a predictable risk to self or others. The risk assessment indicates that planned interventions are effective in minimising but not always eliminating risks. Compliance is variable but usually responsive to planned interventions	High
"Challenging" behaviour of severity and/or frequency that poses a significant risk to self and/or others. The risk assessment identifies that the behaviour(s) require(s) a prompt and skilled response that might be outside the range of planned interventions.	Severe
"Challenging" behaviour of severity and/or frequency that presents an immediate and serious risk to self and/or others. The risks are so serious that they require access to an urgent and skilled response at all times for safe care.	**Priority**

1. Red outline the assessed level above.
2. Describe the actual needs of the individual. Provide the evidence why that level has been chosen, such as the times and situations when the behaviour to likely to be performed across a range of typical daily routines and the frequency, duration and impact of the behaviour.
3. Note any overlap with other domains to avoid double scoring.

My mother's behaviour was challenging in that she was quite restless at times and a risk to herself in falling out of her wheelchair and falling out of bed. There is no record of aggressive behaviour.

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Cognition - This may apply, but is not limited to, individuals with learning disability and/or acquired and degenerative disorders which places them at **risk** of self-harm (including deterioration of health), neglect or exploitation. Where cognitive impairment is indicated, active thought should be given to referral to an appropriate specialist. If this is not considered necessary, record the reason for the decision not to refer.

Description	Level of Need
No evidence of impairment, confusion or disorientation.	No Needs
Mild cognitive impairment for example difficulties in retrieving short-term memory, which requires some supervision and assistance with more complex activities of daily living, such as finance and medication. OR Occasional difficulty with memory and decisions/choices requiring support or assistance, but has insight into their impairment.	Low
Moderate level cognitive impairment that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Awareness of needs and basic risks (for example hot water, fire, abuse) is evident. The individual is able to make choices appropriate to needs with assistance; however, he/she is unable to make decisions about some aspect of their lives, which would put them at risk of harm, neglect or health deterioration.	Moderate
High level of cognitive impairment which is likely to include marked short-term memory issues and maybe disorientation in time and place. The individual has a limited ability to assess basic risks with assistance but finds it extremely difficult to make their own decisions/choices, even with prompting and supervision.	High
Severe cognitive impairment which may include, in addition to lacking short-term memory, problems with long-term memory or severe disorientation. The individual is unable to assess basic risks, and is dependent on others to anticipate even basic needs and to protect them from harm.	**Severe**

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.
3. Where cognitive impairment has an impact on behaviour, take this into account in the behaviour domain, so that the interaction between the two domains is clear.

My Mother had no short term memory, she was unable to retain any basic instruction. She was unable to make any form of decision regarding her own wellbeing. She was very confused and disorientated at times, often very distressed, crying and talking to the wall. She was unable to assess any form of risk, she had several instances of falling out of her wheelchair if not carefully supervised. At mealtimes she often required supervision since she could not discriminate hot food from cold food. She also would put far too much food in her mouth and vomit if not supervised at meal times.

3. Psychological & Emotional Needs: There should be evidence of considering psychological needs and their impact on the individual's health and wellbeing. Use this domain to record the individual's psychological and emotional needs and how they contribute to the overall care needs, noting the underlying causes.

Description	Level of Need
Psychological and emotional needs are not having an impact on their health and wellbeing.	No Needs
Mood disturbance or anxiety, periods of distress, which is having an impact on their health and/or wellbeing but responds to prompts and reassurance. OR Requires prompts to motivate self towards activity and to engage in care plan and/or daily activities.	**Low**
Mood disturbance or anxiety symptoms or periods of distress which do/does not readily respond to prompts and reassurance and have/has an increasing impact on the individual's health and/or wellbeing. OR Withdrawn from social situations, and demonstrates difficulty in engaging in care plan and/or daily activities.	Moderate
Mood disturbance or anxiety symptoms or periods of distress that has/have a severe impact on the individual's health and/or wellbeing. OR Withdrawn from any attempts to engage them in support, care planning and daily activities.	High

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.

There is plenty of evidence that my Mother was distressed at times, not understanding her condition but aware nonetheless that she was ill. She was quite tired and tearful at times having many episodes of "not feeling well" and needing the psychological assurances of her carers. She had no involvement with her care planning.

4. Communication: If individuals have communication needs these should be assessed as part of the MDT assessment. This section relates to difficulties with expression and understanding, not with the interpretation of language.

Description	Level of Need
Able to communicate clearly, verbally or non-verbally. Has a good understanding of their primary language. May require translation if English is not their first language.	No Needs
Needs assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs or may need additional support either visually, through touch or with hearing.	Low
Communication about needs is difficult to understand or interpret, even when assisted. Carers or care workers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Moderate
Unable to reliably communicate their needs at any time and in any way, even when all practicable steps to do so have been taken	**High**

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.

My mother was unable to reliably communicate her needs, relying heavily on her carers to anticipate her needs. In “conversation” she had profound word finding difficulties. She would not initiate any form of conversation, relying on others to talk to her.

5. Mobility: This section considers individuals with **impaired** mobility. Please take other mobility issues such as wandering into account in the behaviour domain where relevant. Where mobility problems are indicated, a Moving and Handling and Falls Risk Assessment should be undertaken (in line with section 6.14 of the National Service Framework for Older People, 2001), and the impact and likelihood of any risk factors considered

Description	Level of Need
Independently mobile (see note above and refer to cognitive impairment/behaviour domains, if appropriate, and include the impact of the person's full mobility on the level of risk).	No Needs
Able to weight bear but needs some assistance and/or requires mobility equipment for daily living.	Low
Not able to consistently weight bear or completely unable to weight bear and able to assist or co-operate with transfers and/or repositioning. OR In one position (bed or chair) for the majority of time and is able to cooperate and assist carers or care workers.	Moderate
In one position (bed or chair) but due to risk of physical harm or loss of muscle tone or pain on movement needs careful positioning and is unable to cooperate. OR At a high risk of falls. OR Involuntary spasms or contractures placing themselves and carers or care workers at risk.	High
Completely immobile and/or clinical condition such that on movement or transfer there is a high risk of serious physical harm and where the positioning is critical.	**Severe**

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, with reference to movement & handling and falls risk assessments where relevant. Describe the frequency and intensity of need, unpredictability, deterioration and any instability.

My Mother was not able to bear her own weight and spent her days in a wheelchair, carers re-positioning her on a regular basis as she seemed to find a wheelchair uncomfortable, moving forward a lot or leaning towards the left or right. Transfer to her bed and to the toilet was with a 2 carer hoist assist (on occasion 3 carers) often crying out during transfer as she had a fear of falling and needed to be regularly comforted. Because she had painful flexion deformity in her knees, this pain also added to her discomfort during transfers. Special cushions were purchased for her wheelchair and the hoist sling to minimise pain. Because of general immobility she needed to be turned regularly in bed to minimise pressure areas and soreness although from 4-9-1998 to 1-1-2001, there are 44 recorded episodes of soreness and skin irritation (groin, buttocks, shoulders, hips) requiring application of skin creams. She required assistance to dress, her co-ordination was very poor. General injury risk of falling out of bed or out of her wheelchair. She had no understanding of her limitations and was unable to retain advice, co-operate or comply with instructions so this manifest unpredictability made it difficult for carers. Her bed was fitted with rails and a lap strap was used on her wheelchair but even so, there were unavoidable instances of injury.

6. Nutrition – Food and Drink: Individuals at risk of malnutrition, dehydration and/or aspiration should be assessed and any management and risk factors supported by a management plan.

Description	Level of Need
Able to take adequate food and drink by mouth to meet all nutritional requirements.	No Needs
Needs supervision, prompting with meals, or may need feeding and/or a special diet. OR Able to take food and drink by mouth but requires additional/supplementary feeding.	**Low**
Needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed. OR Unable to take any food and drink by mouth, but all nutritional requirements are being adequately maintained by artificial means for example via a non-problematic P.E.G.	Moderate
Dysphagia requiring skilled intervention to ensure adequate nutrition/hydration and minimise the risk of choking and aspiration to maintain airway. OR Subcutaneous fluids that are managed by the individual or specifically trained carers or care workers. OR Nutritional status "at risk" and may be associated with unintended, significant weight loss. OR Problems relating to a feeding device (for example P.E.G.) that require skilled assessment and review.	High
Unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration for example I.V. fluids. OR Unable to take food and drink by mouth, intervention inappropriate or impossible	Severe

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.

On the initial admittance summary at Sidegate Lane, it states that my Mother needs her food cut up, she has no idea what to do with a knife and fork so feeds herself with a spoon. She needed monitoring to ensure that she didn't put an excess of food in her mouth without swallowing. She was assessed by Dr.Raj in December 1998 as having a choking risk. From 4-9-1998 to 1-1-2001, the daily record finds that she put too much food in her mouth causing her to vomit on 18 occasions..

7. Continence: Where continence problems are identified, a full continence assessment should be undertaken, any underlying conditions identified, and the impact and likelihood of any risk factors evaluated.

Description	Level of Need
Continent of urine and faeces.	No Needs
Continence care is routine on a day-to-day basis; Incontinence of urine managed through for example medication, regular toileting, use of penile sheaths etc. AND Is able to maintain full control over bowel movements or has a stable stoma, or may have occasional faecal incontinence.	Low
Continence care is routine but requires monitoring to minimise risks, for example those associated with urinary catheters, double incontinence and/or the management of constipation.	Moderate
Continence care is problematic and requires timely and skilled intervention.	**High**

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.
3. Take into account any aspect of continence care associated with behaviour in the Behaviour Domain.

Doubly incontinent, changed regularly both day and night. During 1999 she had bowel movement problems resulting in regular visits from either a district nurse or doctor as detailed in the daily record sheets to administer enemas.

8. Skin (including tissue viability): Evidence of wounds should be given by completing a wound assessment chart or tissue viability assessment. Here, a skin condition is taken to mean any condition which affects or has the potential to affect the integrity of the skin. Please note that the phrases in the descriptors are taken from the Stirling descriptors/NICE

Description	Level of Need
No evidence of pressure damage or skin condition.	No Needs
Evidence of pressure damage; and/or pressure ulcer(s) either with "discolouration of intact skin" or with "partial thickness skin loss involving epidermis and/or dermis"; or a minor wound. **OR** A skin condition that requires clinical reassessment less than weekly.	Low
Pressure damage or open wound(s), pressure ulcer(s) either with "partial thickness skin loss involving epidermis and/or dermis", or "full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule", which is/are responding to treatment. **OR** A skin condition which requires a minimum of weekly reassessment and which is responding to treatment. **OR** High risk of skin breakdown which requires preventative intervention several times each day, without which skin integrity would break down.	**Moderate**
Open wound(s), pressure ulcer(s) with "full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule" which are not responding to treatment and require a minimum of daily monitoring/reassessment. **OR** A skin condition which requires a minimum of daily monitoring or reassessment. **OR** Specialist dressing regime in place which is responding to treatment.	High
Open wound(s), pressure ulcer(s) with "full thickness skin loss with extensive destruction and tissue necrosis extending to underlying bone, tendon or joint capsule" or above. **OR** Multiple wounds which are not responding to treatment.	Severe

1. Red outline the assessed level above.
2. Describe the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.

There are 44 recorded episodes of soreness and skin irritation (groin, buttocks, shoulders, hips) in the daily record requiring application of skin creams etc. plus some nightime requirements over the period 4-4-1998 to 1-1-2001. It would appear that my mother had serious skin irritation problems that she would constantly scratch at night, The itching and scratching was a major issue not very well under control. In 2002, there were 330 doses of Chlorophenramine given. Also in 2002 there were 146 records of skin cream application and 4 records of blistered skin.

9. Breathing

Description	Level of Need
Normal breathing, no issues with shortness of breath.	**No Needs**
Shortness of breath which may require the use of inhalers or a nebuliser and has no impact on daily living activities.	Low
Episodes of breathlessness which do not respond to management and limit some daily activities. **OR** Requires any of the following: - low level oxygen therapy (24%). - room air ventilators via a facial or nasal mask. - other therapeutic appliances to maintain airflow.	Moderate
Is able to breathe independently through a tracheotomy, that they can manage themselves, or with the support of carers or care workers. **OR** CPAP (Continuous Positive Airways Pressure). **OR** Breathlessness due to symptoms of chest infections which are not responding to therapeutic treatment and limit all activities of daily living activities.	High
Difficulty in breathing, even through a tracheotomy, which requires suction to maintain airway. **OR** Demonstrates severe breathing difficulties at rest, in spite of maximum medical therapy.	Severe
Unable to breathe independently, requires invasive mechanical ventilation.	**Priority**
1. Red outline the assessed level above. **2. Describe below the actual needs of the individual providing the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.**	

10. Drug Therapies and Medication: Symptom Control - The individual's experience of how their pain and other symptoms (where these symptoms are not accounted for in other domains such as the Altered States of Consciousness and Psychological and Emotional Domains) are managed and the intensity of those symptoms is an important factor in determining the level of need in this area. Where this affects other aspects of their life, please refer to the other domains especially the psychological and emotional domain. The location of care will influence who gives the medication. In determining the level of need, it is the knowledge and skill required to manage the clinical need that is the determining factor. In some situations, an individual or their carer will be managing their own medication and this can require a high level of skill.

Description	Level of Need
Symptoms are managed effectively and without any problems, and medication is not resulting in any unmanageable side effects.	No Needs
Requires supervision/administration of and/or prompting with medication or may have a physical, mental state or cognitive impairment requiring support to take medication, but shows concordance with medication regime. **OR** Mild pain that is predictable and/or is associated with certain activities of daily living. Pain and other symptoms do not have an impact on the provision of care.	Low
Requires the administration of medication due to: • Non-concordance or non-compliance, • Type of medication (for example insulin), or • Route of medication (for example PEG, liquid medication). **OR** - Moderate pain which follows a predictable pattern; or other symptoms which are having a moderate effect on other domains or on the provision of care.	**Moderate**
Requires administration of medication regime by a registered nurse or care worker specifically trained for this task, and monitoring because of potential fluctuation of the medical condition or mental state, that is usually non-problematic to manage. **OR** - Moderate pain or other symptoms which is/are having a significant effect on other domains or on the provision of care.	High
Requires administration of medication regime by a registered nurse or care worker specifically trained for this task, and monitoring because of fluctuation of the medical condition or mental state, that is usually problematic to manage. **OR** - severe recurrent or constant pain which is not responding to treatment **OR** - Risk of non-concordance with medication, placing them at severe risk of relapse.	Severe
Has a drug regime that requires daily monitoring by a registered nurse to ensure effective symptom and pain management associated with a rapidly changing and/or deteriorating condition. **OR - Unremitting and overwhelming pain despite all efforts to control pain effectively.**	**Priority**

1. Red outline the assessed level above.
2. Describe below the actual needs of the individual and provide the evidence why that level has been chosen, including the frequency and intensity of need, unpredictability, deterioration and any instability.
3. Note any overlap with e.g. the Behaviour and ASC Domains to avoid double scoring.

During the period 25-9-98 to 1-1-2000, there are 9 recorded doctor visits and 30 district nurse visits for a variety of problems, eg eye disorders, blisters, bleeding teeth, constipation etc. Pain relief was given on a regular basis. From Dec.2001 to Oct.2002, 220 Chlorophramine tablets were given, 879 CoCodamol tablets' 340 doses of Sphagula, 670 doses of Lactulose and 300 doses of Senna.

11. Altered States of Consciousness (ASC)

Description	Level of Need
No evidence of altered states of consciousness (ASC).	**No Needs**
History of ASC but effectively managed and is at a low risk.	Low
Occasional episodes of unconsciousness that require the supervision of a carer or care worker to minimise the risk of harm.	Moderate
ASC that require skilled intervention to reduce the risk of harm.	High
Coma. **OR** **ASC that occur on most days, do not respond to preventative treatment, and result in a severe risk of harm.**	**Priority**
1. Red outline the assessed level above. **2. Describe below the actual needs of the individual providing the evidence why that level has been chosen (referring to appropriate risk assessments), including the frequency and intensity of need, unpredictability, deterioration and any instability.**	

Other significant care needs to be taken into consideration

- It is very clear from the daily record sheets that my Mother's condition started to rapidly deteriorate in 2002
- Some instances reported where my mother was actually unable to swallow food.
- STARS assessment 10-1-2002 was 64/136 indicating very high needs
- STARS assessment 17-10--2002 was 53/136 indicating very high needs

Assessed Levels of Need

Care Domain	P	S	H	M	L	N
Behaviour					X	
Cognition		X				
Psychological Needs					X	
Communication			X			
Mobility		X				
Nutrition – Food & Drink					X	
Continence			X			
Skin (including tissue viability)				X		
Breathing						X
Drug Therapies & Medication				X		
Altered States of Consciousness						X
Other significant care need (see above)						
Totals		**2**	**2**	**2**	**3**	**2**

From the DOH Decision-Support Tool for NHS Continuing Healthcare document dh-09518, it states that a clear recommendation for NHS Continuing Healthcare would be expected in either of the following cases:-

- A level of **priority** needs in any one of the four domains that carry this level.
- A total of two or more incidences of identified **severe** needs across all care domains