

“How Can You Really See me if You Don’t Get to Know me?”

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Aim of Project

- To develop a new **holistic assessment tool** for the **hospice inpatient unit** that would;
 - help facilitate a better understanding of the **individual** behind a diagnosis of a **Dementia** – to *capture* the *essence* of the person
 - to provide better **person centred care**
 - to hopefully **enrich** the lives of **patients** in our care and their **loved ones**.

Rationale for Project

- The numbers of patients with a diagnosis of a dementia admitted to the hospice has been increasing.
- Individuals with a dementia and their carers/families are *experts* in their own care and their *voices need to be heard*
- I identified the need to improve the holistic assessment tool In the hospice inpatient unit;
 - This was useful clinically
 - Lacked domains to facilitate a better understanding of the individual *behind* their diagnosis.

Dementia Champions Programme

I enrolled in the Dementia Champions Programme (DCP)

- Facilitated by *North West Regional College*
- Developed and provided in partnership by the *HSCB, The Public Health Agency, Connected Health, DOH and Atlantic Philanthropies.*
- *DCP* encouraged the development of *changes* that would help improve care, experience and outcomes for individuals and their loved ones living with a diagnosis of a dementia.
- *Through the Dementia Champion Programme I undertook a change project initiative to improve the holistic assessment tool at our hospice.*

Choosing The Right Document

- Research of literature identified a number of potential tools
- I chose the “Getting to know me” document by *Alzheimer's Society Scotland* as I believed it to be clear, concise in its nature and easily followed and integrated into our hospice care.
- Supported by;
 - Foundation of National studies Dissemination 2010. Vol5 No 5; stated the document will *help staff reflect on and improve their current practice.*
 - Government of Scotland website endorses this as it encourages individuals and their loved ones to participate in care, which encourages a *team effort.*
 - Fits with the Triangle of care approach (patient/ carer/professional)as it promotes a meaningful environment as both parties are *involved in the decision making process.*

Anticipated Benefits

- *Empower individuals* living with a dementia by ensuring an *equal partnership*
- Help ensure individuals and their loved ones/advocate get their *voices heard*.
- Help ensure the qualities that make the person are captured,.
- Ensure loved ones/carers and family feel recognised, valued and involved.
- Build *teamwork* by strengthening relationships between individuals / families and staff.
- Provide *security* and peace of mind/ help build trust
- *Smooth the transition* from home to hospice and vice versa
- Helping staff become *proactive* rather than *reactive*.
- Strengthen current risk assessments
- To hopefully improve quality of life and well being

Approach

- Adapted the '*Getting to know me*' document for hospice inpatient unit and accompanying guidance notes for the hospice IPU.
- A prospective pilot was undertaken;
 - *Short time frame* due to course deadline- only 2 patients with a diagnosis of a dementia were admitted into the hospice during this time frame
 - Staff needed to be updated on revised tool
 - Distributed to patients and their families to complete with the help from staff where required.
 - Once pilot was completed we needed to roll the project out following feedback

'The Getting To Know Me Document'

“Getting to know me”

This document will be used to help staff best support you during your time here at Foyle Hospice, we would like to get to know you better. We invite you, your family, friends and carers to help nursing staff complete this document. We will store this in your personal notes. You can add as much detail as you want.

My Name; this is my full name and the name I like to be called

The person who knows me best; the person I would like you to call if ever I need anything or if I find myself in an emergency or whenever I just need someone close.

Home, family and things that are important to me; do you have any pets, home comforts that are precious to you? Personal items that are important to me this is what I want close to me at all times.

I would like you to know; anything that will help staff get to know you, maybe the things that you do to help relax you or things that annoy or upset you.

My story/life so far; did you work in your past? If so what did you do? What are your interests, hobbies, what dates are important to you?

Things I think you should know about my spiritual beliefs; when I am in the hospice this is what I would like/dislike, this is who I would like to visit me, and this is what will bring me comfort.

Food and drink; this is what I like to eat, what I dislike, I may have some difficulty eating certain food and may need help, if so how would I like the nurse or carer to help me with my food. I may have a certain way that I like my food presented.

Taking medication; this is how I like to take my medication, do you need any help?

Sleep and rest; this is what I like to do during day, this is what I need to help me sleep and the time I usually go to sleep at.

Washing and dressing; this is how I like to get dressed, for e.g. do I like to put my trousers on first or shirt first what is my routine, what time do I like to get washed and dressed. If I need help I would prefer male or female carer

Communication, my hearing and eyesight; please note when was the last time I truly felt listened too, why was that? What did it make you feel? How did it make you feel about the person who listened? Do I wear glasses?

How I get about; this is my mobility, this is how I would like you to help me etc around indoors and outdoors if I need help. Do I require any walking aids to support me.

For your friends, carers and family; They are invited to add if you like details on what they feel is important for staff at hospice to know, how would they like to be involved in your care whilst you are here, would you like them to help during meal times, each times, or just to be there when you need them when you are feeling a little anxious or afraid.

Thank you for taking this time to complete you're getting to know me document, this document holds very important information that staff at Foyle hospice will hold securely at the front of your confidential notes. This information help us to get to know you better, your personality what makes you, you.

Thank you.

The Guidance Notes

Guidance notes for staff to follow, these notes will help you think about further questions to prompt the individual family or friends in an attempt to dig deeper into the world of the person living with dementia. We need to see the real person behind this disease and not get that person lost.

My name; this is the name that the individual would like you to call them by, the name that brings them comfort and ease and familiarity.

The person who knows me best; this will be the person that brings comfort to the individual during times of happiness or distressed times, this individual should be approached to let them know this and be available in an emergent situation to be contacted. My advocate in the outside world.

Home, family and things that are important to me; this is my home comforts, does the individual know that they can bring these in at any time to help them adjust during their stay at hospice. Family members that I would like to see as they are important to me. Does the individual have any pets at home that they may be concerned about could they organise with staff for family members to bring this pet in often so they can relax and feel secure.

I would like you to know; my likes and dislikes, during times of distress this is how I cope, is it just sitting with someone who has the time to comfort me, playing music that I often listen to, to get a little help from staff to take me a walk outside. What does the individual not like, do you pick up on cues that one member of staff asking questions or providing direction is enough, does the individual appear to get more agitated when staff are talking around him/her. Is the lightening in the room suitable, does noise affect the individual if so how do they react?

My life so far; this could be past and present employment, this is particularly important here as often the persons job in past may be reflected in certain behaviours that they may be presenting, having an insight to this may help staff support the individual during times of distress. What dates are important to the individual what memories to they bring to the individual again being aware of key events in the individuals life will help foresee and pre-empt certain situations.

My spiritual considerations; esp. if the individual is aware that they are in hospice care this may open up a lot of emotions for the individual they may find difficulty trying to express these, they may not be a person who is spiritual but have certain beliefs that make them happy and content and we need to know these, do they want a priest or Chaplin to help bring spiritual comfort or are they happy to do this on their own. As nurses in hospice care please be reminded here for an accurate holistic approach psychological, social, spiritual and practical support which takes into account past experiences and current situations should all be explored.

Food and drink; this is how I enjoy food, am I having difficulty at present, this can be backed up with our current risk assessments esp. oral assessments etc. Does the individual require help when eating if so how much help is required? Does the person require you to assist in feeding or simply helping to cut up certain foods, all staff to be mindful here that we are not taking away the individuals independence by not knowing this and simply assuming they cannot do it? What are my likes and dislikes regarding food? Can the hospice chef meet with patient and their families to discuss alternative food options? Does the individual require more time during meals noting as their dementia progresses the ability to recognise the process of eating deteriorates.

Sleep and rest; this is the individual's normal routine at home, if sleep is an issue this is what I try at home to help me. Does the dark frighten the individual? What time do I usually get up at and go to bed, staff to try as much as possible to encourage this routine whilst in hospice to help the individual adjust. Does the individual require or like to take naps in the afternoon?

Taking medications; staff to inform individual and family that certain times of medications may change from times taken at home when they are admitted to us however we will try our utmost to try and help the individual with this reassurance and support to be constant. This is the way I, like to take my medication, I like certain tablets to be taken first, what process does the individual take their medication at home.

Washing and dressing; this is how the individual likes to do things they may not be able to tell you but vital information from carers and family will help direct, be mindful many triggers of distress are evident during times of washing and personal care as individuals may feel embarrassed, unsure of a new face, have specific routines i.e. liking their shirt or blouse on last certain routines of dressing in morning may be different to what we deem as the norm but this is what this individual likes to do , being mindful of any changes to this may cause distress and deem the individual as being challenging.

Communication , hearing and eyesight; this is important here as we can if the individual is able to dig deeper and get an insight into when the individual a time they felt truly listened to, how it made them feel? I think hearing this will enable us as nurses to reflect upon our current practice and look at ow we communicate at present. Does the individual require a quiet setting, are there any hearing problems? What time of day suits the individual better for assessments ward round with doctors etc., are they more settle din morning as to the afternoon where individual is tiered and sleepy?? Do you get more interaction from the individual when you are at their eye level?

My mobility; this is how I like to get around , this is how I normally get around, risk assessments will further back this up for safety. Does the individual require assistance or just feel contented knowing that someone is there when I need them. Does the individual require a walking aid? Or would they benefit from physio assessment etc. Does the individual like to go for little walks during the day?

Family and friends; this could be the ideal time to talk with family member friends and carers, get to know what their concerns and worries may be and how we in the hospice can best. Families tend to be the best advocate, carers nada visors for individuals in our care. Dementia affects the families as well as the patient. Families may have their own distress and it's important for us to see what we can to help them adjust to their loved one being moved to a different environment. This section allows us as nurses to gain the family's perspective on what they feel we should know about the individual.by dong this at the hospice we are ensuring we are involving the family in decision making, admissions, discharge planning, signposting, and treatment options.

Thank you for your time and cooperation.

Feedback

- Well received by families and staff
- Staff valued the additional information about the person that was vital to understanding and meeting specific care needs.
- Families appreciated and felt reassured by staff taking the time to know their loved one; truly understanding their unique personalities.
- Challenges for change for staff, fear of change and will it bring more paperwork.
- Concerns addressed by some members of staff that having a separate holistic assessment tool for individuals living with a dementia, may have the potential to stigmatize.

Closing Remarks

- Participation of hospices in programmes such as the Dementia Champions appear to help improve staff knowledge/ awareness and possibly care.
- This pilot indicated that the Getting to know me document can be a useful component of holistic assessment in hospices and appears to increase the confidence amongst patient and their loved ones / the reality of their world is better understood.
- It helps staff to ask the right questions
- The adapted Getting to know me document is being fully implemented.
 - for all patients admitted to the hospice regardless of diagnosis
 - additional staff education underway to assist full implementation
 - Aiming for the document to be completed within 48 hours of admission.

Collaboration between hospices, higher education colleges, dementia charities and other organisations is crucial in meeting challenges and innovation care.

Charities such as Alzheimer Scotland are a rich resource and other organisations for individuals with a diagnosis of a dementia.

Thank You For Listening

For any further details please contact;
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