

This is Me

Ian Stirling, Lena Baird, Susan Campbell, Lynne Carmichael, Margaret Cassidy, Margaret Follett, Fiona Irvine, Marion Mathieson and Vicki Revie

Ayrshire Hospice

Making today matter

Aims

'Understanding a little bit about who you are, your family and the important people in your life, your home circumstances, the stories and experiences that have shaped your life, your interests, routines and what really matters to you, can all help us care for you more effectively and personally.'

The Problem

Critical reflection on case studies of people with communication difficulties, particularly in the later stages of an illness, highlights how if we don't know what matters and what is important to people then this can compromise the quality of care, leading to unnecessary distress whether physical, emotional, relational or spiritual.

'Gordon's story':

Gordon had advanced motor neurone disease and was unable to speak or use his lightwriter. His wife Eve said that many of Gordon's conversations are characterised by people giving up and apologising that they couldn't understand him. One day I could see that he was really distressed but couldn't express what was on his mind. I made a commitment to him, 'together we would find out what was troubling him' ... after many hours of patiently working together, using a communication tool I had created, Gordon was eventually able to convey the source of his spiritual distress, "God has given me all these gifts and I still have much to share, especially with my grandchildren. Why has He stopped me from being able to do this?" (Jane, hospice chaplain)

A Solution

Further reflection and a review of the literature by the multidisciplinary team at the Ayrshire Hospice emphasises the need of a person-centred document, 'This Is Me', which enhances the scope and depth of communication between patients, their families and the multidisciplinary team not just towards the end of life when it may be too late, but from the time of initial diagnosis through to end of life care.

Ayrshire Hospice
This is me
What really matters to you...
Understanding a little bit about who you are, your family and the important people in your life, your home circumstances, the stories and experiences that have shaped your life, can all help us care for you more effectively and personally.
This is Me can be completed either by you or by someone who knows you well.
My full name

This is Me Document

Home

Tell us about your home, include the place where you live, who lives with you, any pets, what your home is like and what it is that makes it feel like 'home'

Past Interests

Describe some of the activities you have enjoyed doing in the past. Include musical interests, sporting interests, gardening, clubs and voluntary work. Are you still able to do these? If not, why not?

Communication

People communicate in different ways. How do you usually communicate?

Worries, Hopes And Fears

Include anything you may find troubling, eg family concerns, being apart from a loved one. List environmental factors that may make you feel anxious eg open doors, loud voice or the dark

What Makes You Feel Better If You Are Anxious Or Upset?

Include things that may help if you become unhappy or distressed eg comforting words, music or TV. Do you like company and someone sitting and talking with you or do you prefer quiet time alone?

A Strategy

The 'This Is Me' document is developed, and piloted across all areas of the organisation to enable timely conversations to take place, key information to be shared, improve collaboration in decision-making, create solid foundations for care plans and offer person-centred care.

'Jenny's Story'

The key thing was communication because she couldn't communicate. Frustrated and angry, that's what Jenny was. But once you made the relationship if you zoned in and got that connection she would talk and talk and talk. I stood there with the communication board, got to know about her bowling and life and she was no longer angry and frustrated because she was being heard so to speak. The change in that woman was night and day. She laughed, she wanted to talk, she was more content and instead of saying I want to go home she said I want to stay.

Evaluation

An extensive evaluation of the pilot project allows the This is Me project group to continue to refine the document and consider how best to embed the philosophy of person-centred care across the hospice.

'This has got to be the most in depth information we have about John.' (OT)

'This is a comprehensive guide to "Me" – I hope it works well for you all.' (Wife)

Methodology

An Action Research methodology, which emphasises collaboration, transformation and a spiral of self-reflective cycles, offers a rigorous framework for the project (see figure 1).

Action Cycle 1

Reflection on MND case studies identifies the need for excellence in communication.

Action Cycle 2

Plan, pilot and evaluate 'This Is Me' document to enhance communication for all patients.

Action Cycle 3

Embed 'This is Me' across the organisation.

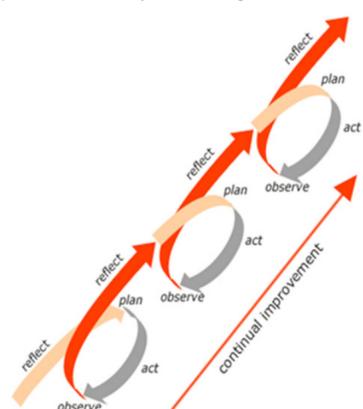


Figure 1
This figure

illustrates the spiral model of action research adopted in the project

Personal Evaluation

Eighteen evaluation forms were returned (three blank), indicating that people found the document easy to complete, covered all key areas and were primarily completed in collaboration with either family or healthcare professionals – one person said that 'I found it good to talk' and another that 'it seemed very long, but once I understood what it was for I didn't mind doing it'.



Timely conversations:

'I don't want to go into a care home' (IPU)

Key information to be shared:

'I tend to keep things to myself'. (Solas)
'My husband is the person who is closest and knows me best'. (IPU)
'I'm a bit worried about pain ... I want to die at the hospice'

Improved collaboration

'I would like a device to use a kindle' → passed on to OT
'Being a member of the church is very important to me' → passed on to chaplain

Designing of care plans

'I would like to die at Ibrox' (IPU)
'I am unable to get up on my own and walk without fear of falling' → passed on to team
'When I am anxious I like listening to classical music' → passed on to OT
'I have already made my will' → no need for further conversation

Person-centred care

'I like to read the paper in the morning with a cup of tea' → passed on to day services team
'I prefer Cadbury's chocolate'.
'Since being unwell I am scared of the dark'.

Staff Evaluation

All staff said that when used flexibly and imaginatively 'This is me' allows for timely conversations, key information to be shared, improved collaboration, designing of care plans and person-centred care.

'This is Me' gives you permission to talk' (OT)

'It is a really good way to get to now patients and their families ... not rushed ... time ... one to one' (Respite and Response team)



Thirteen staff, from various professions across the hospice, including specialist palliative care community nurses, respite and response care assistants, IPU and Day Services care assistants, staff nurse, occupational therapists, chaplain, social worker completed staff evaluation forms.

Area of work	
Respite and response	1
SOLAS community team	4
SOLAS day services	2
IIPU	2
AHP	4

Evaluation shows that the document was best completed when in collaboration with either family member or healthcare professional. Completion rates deteriorated when the document was merely handed to the individual to complete.

The document is easy to complete?

(Very easy, 7; Fairly easy, 6; Difficult, 0)

Although some areas, such as beliefs were harder to engage with, often related to profession which suggests a need for further training to build confidence. Nothing was identified as missing from this document though more space to allow scope for longer answers is seen to be advantageous?

Overall staff found that 'This is me' enhances the scope and depth of communication.

However the depth does vary from person to person, and depends on context. Some found the document to be an excellent trigger for conversation; others found the document to be ideal for capturing essential information

'This is me' is a communication tool that is easier to complete in the early phases of care and less so as one approaches end of life of care.

The reasons for this center upon having more time in the early stages, and anxiety about the potential real and perceived burden being imposed towards latter stages of care.

The document is found to be useful in transition moments when a person moves from one area of care to another;

However one member of staff said that 'they were unable to complete due to work time restrictions' illustrating that person-centred care takes time. Other staff identified that 'duplication with other forms such as ACPs is causing confusion to external staff' suggesting that some streamlining of documentation is required and one person held back 'for fear of burdening the patient'. Some staff say "I don't have the time to read that ... but you have to make the time and get to know the patient."

Findings

On-going evaluation, using both questionnaires and interviews, so far indicates the positive benefits of 'This Is Me' as a communicative tool throughout the illness trajectory. It is being used in the community, in Day Services and in the In-Patient Unit. Two final quotations, one from a staff member and another one from a family illustrate the impact and potential of "This is Me."

Recommendations

The following recommendations will form the basis of Action Cycle 3, whose aim is to embed 'This is Me' across the organisation:

- Redesign the document
- Incorporate 'This is Me' into the hospice computer system
- Create information leaflets for patients, families and staff
- Encourage hospice staff to complete 'This is Me' through training and education
- Ensure that the information within 'This is Me' complements and informs the care plans which are currently heavily based on clinical assessment forms

Conclusion

The 'This Is Me' project is enhancing the depth of communication between patients, their families and the multidisciplinary team within the Ayrshire Hospice. 'This is Me' allows staff, patients and carers to enjoy timely conversations, share key information, improve collaboration, create solid and offer person-centred care.

'one gentleman felt valued, because 'This is Me' showed that the service was interested in him as a person.'

Contact

For further information please contact: Ian Stirling, ian.stirling@ayrshirehospice.org