Making Every Moment Count

Developing a Guide for “Everyone Supporting Someone”!!

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Firstly… a little bit about me!

- One of 4 AHP Dementia Consultants
- Funded by Scottish Government
- Based in NHS Lanarkshire
- National remit for activity, participation and environment
Where to start?
What do we even mean by activity?
How can we make an impact?
What would make a difference?
Find a foundation to build on!
WHO ICF Model ……Great!!!!
And now….so that we are all talking about the same thing!!!!!!

**ACTIVITY**

“the state of being active or busy” “Something that people do especially for pleasure, interest, exercise etc.”

**PARTICIPATION**

“to take part or be involved in”

WHO ICF “Involvement in a life situation

**ENVIRONMENT**

“the surroundings or conditions within which something or someone exists”

“the combination of external conditions that surround and influence a living organism”
Why is “activity” important

- NICE Guidelines indicate activity is essential to human health and wellbeing with the potential to restore, maintain and improve physical and mental health.


Lots of good policy to relate to!

- “Charter of Rights for People with Dementia and Their Carers in Scotland”
- “Remember I’m Still Me”
- Scotland’s National Dementia Strategy
- Standards of Care for Dementia in Scotland
- “Promoting Excellence”
- NHS Quality Strategy
- Personalisation agenda
- Care and Compassion in Practice
- Person centred outcomes

So strong strategic and policy basis to work from!!!
Creating “Make Every Moment Count”

The Beginning
We set up a partnership group

- Representatives from NHS, CI, LA, AS and BUPA
- First meeting in December 2011
- The group recognised that there is a huge amount of material and information “out there” but how to access and communicate what is of quality and helpful to the end user.
- Developed an ambitious project plan
- Launch in Autumn 2012
We asked ourselves some questions

- Who will use the resource?
- What does it need to be able to do?
- What features should it have?
- What are the design issues?
- What are the challenges to achieving our vision?
- What are the implications of producing such a resource?
Issues about terminology

- Differing expectations of “activity”
- “Activity” means different things to different people
- Activity Coordinator posts. These are to coordinate and not to be sole provider of activity. This role can be misinterpreted by virtue of the title.
- Is there too much reliance on activity programmes and group activities?
- “Activity” must suit the individual and ensure it has meaning and resonance for the person.
- Quality of Life and Quality of Care ....both are important in the care setting for inspection purposes but they are not the same thing.
How to evidence?

- How to capture the meaningful moments that occur during the caring process...
- How to record the often unseen, unplanned, subtle and fleeting but which has significance, relevance and importance to the person
- How to evidence the feelings that people have and show
- How to evidence the approach that we want...what guidance do we need to produce...what are we trying to achieve?
- We need paperwork that documents our desired approach to provide evidence for inspection purposes etc
- We need to suggest more creative ways to capture and evidence this approach in practice
It is about a cultural change!

- Need for a cultural shift away from the idea that “activity” is an add-on or involves anything “fancy”. It needs to be redefined as the ordinary everyday things that people do in the course of a purposeful day.

- There should be a general philosophy apparent in all care settings that emphasises “My Life” “Living My Life” & “How I Want to Live”

- We need to change mindset and expectations of staff and the general mainstream community and build confidence regarding this agenda
In other words.....Activity?.........
It’s Everyone’s Business!
We looked at the evidence

- What works?
- How do we know?
- Literature review (activity, rehabilitation, dementia)
- Large body of evidence – benefits of physical activity (falls work, benefits to health and wellbeing) (particular focus on this at the moment)
- Reminiscence, music, Snoezelen
But there is **NO** such thing as a "gold standard" "fits all" activity programme......

The true focus is not the activity itself but the quality and joy of the interaction.
What should it look like?

- Have clear statements, hints and tips
- Written in plain English i.e. everyday language
- Describe principles and emphasise individuality, personhood and personalisation
- Give guidance
- Have wide “organisational fit”
- It should include the importance of paying careful attention to environmental factors
- It should balance health and safety elements with positive risk taking
- It should ensure that the importance of physical health and wellbeing, and importance of exercise is emphasised.
- It should emphasise the importance of grading activity to the individual taking account of physical and mental health and wellbeing status, personal preference and relevance to the individual.
- It should encourage staying connected to personal and social communities and encourage links with mainstream community.
- It should encourage in-reach from mainstream community.
- It should include the importance of meeting spiritual needs and spirituality.
Physically it should “fit in your pocket”

It should emphasise that “anyone can do it” and it is “everyone’s business”

It should meet the needs of frontline staff in care settings across all social and health care and should be designed to have a resonance and fit with “Promoting Excellence”

It should be “covetable” “appealing” “attractive” “substantial” “have impact” “be powerful” “easy to read, understand and use” “meet expectations” “memorable” “principles into practice” empower” “be the penny that drops” “be catchy”

It should be inspirational !!!!!!!
Tall Order... *Capture a world of meaning...*

- Don't count the days, make the days count
  - *Muhammad Ali*

- Life isn't a matter of milestones, but of moments.
  - *Rose Kennedy*
........But keep it simple!!!!

"All New, Life-Affirming Formula"?
1 dunno, 1 kinda just want to wash my hair.
Together we agreed........

- Activities for people with dementia should always be created with an aim to improve social, emotional and spiritual well-being,

- “Meaningful” activities are created to tap into a person's past skills, memories and interests.

- Activities do not have to always be structured but do need to stimulate the senses and encourage participation, boost self-esteem and fulfil spiritual and emotional needs.

“What you and I can do to make my day, from the moment I wake up, to the moment I go to sleep”
Deceptively simple!
MEMC has 5 key messages............

- Get to know me
- It’s not just what you do….it’s how you make me feel
- Know what I can do and support me to do it
- Help me feel comfortable, safe and secure in my surroundings
- Remember little things all add up
We gave ourselves big shoes to fill!

- See the person not the illness
- Evidence based
- Resonate with Standards of Care for Dementia in Scotland (written in the first person)
- Fit with Care Standards
- Personalisation and the uniqueness of the individual and their journey
- Person centred care in practice
- Care and Compassion in practice
- Support wide organisational aims and objectives
- Demonstrate spirituality
- Support recording keeping
- Be in everyone's language
- QUALITY OF CARE and QUALITY OF LIFE
But we think we have done it!

“*It recognises that everybody has a part to play in the unit*”

“I *now approach all interactions as an activity*”

“I encouraged a patient to be more active in their care, giving time to carry out activities no matter how small. I have seen an improvement in her self confidence”

“It is a refreshing change to include the concept of activity as an everyday thing we all do”

“It made me realise that that each person has had a past and is entitled to a future no matter what their circumstances”
I had a patient who was not too happy. She had a son who visited her regularly but that seemed to make no difference to her mood.

I noticed she had a picture of a Jack Russell on her locker and I found out its name was Lucky. So I asked her son if he could bring Lucky in to see her.

He informed me the dog was in the car so he got the dog and I got a wheel chair for the lady. They went outside as it was a lovely day. It was all smiles for Lucky!!!

That was a positive change and made every moment count!
To affect the quality of the day, that is the highest of arts.

*Henry David Thoreau*
"Make Every Moment Count"
Autumn 2012

SOMETIMES you will never know the true value of a moment until it becomes a memory.

{unknown}