



Little messages



Introduction

This is a book of 'Little Messages' with big meanings, created by the 'What's Life Like?' group in Barnsley.

It is a book for people without dementia, looking in, to understand how we feel and think about life with dementia. It is also a book for people with dementia to encourage and support their journey.

We hope you will read and use these messages in your contact with all people living with dementia.

The 'What's Life Like?' group is an involvement group facilitated and supported by staff and volunteers from Alzheimer's Society in Barnsley.

Dear Doctor...

Dear Doctor...

'Talk to me first don't talk over me. Listen to what I have to say'.

Dear Doctor...

'Consistency in patient care is important – let us see the same Doctor, read my notes'.

Dear Doctor...

‘Check that the person wants to know the diagnosis before you tell them’.

Dear Doctor...

‘It is important to involve my ‘carer’ in conversations’.

Dear Doctor...

‘Take time to find out about me, and what interests me as a person’.

Dear Doctor...

‘Don’t assume I understand about dementia, give me time to ask questions’.

‘Give the right information
at the right time to the
right person’.

Dear Doctor

There’s a way to tell us that we have dementia. When you say ‘there isn’t anything you can do for me’ I feel angry, upset, frustrated. I don’t think my life is over.

It would be nice if you would have said ‘I am so sorry. Let’s see what we can do to help...’ Talk to me – what is the next step?

Yours faithfully
Person with dementia

Dear person with dementia...

Dear person
with dementia...

‘Accept the diagnosis and
carry on – do what you’ve
always done’.

Dear person with dementia...

‘Don’t stop doing everything
just because you’ve
got dementia.’

Dear person with dementia...

‘Carry on doing what
you know and the things
you can still do’.

Dear person with dementia...

‘Keep learning new things’.

Dear person with dementia...

‘Keep doing different things
and meeting people’.

Dear person with dementia...

Dear person with dementia...

‘It’s important to still interact – to have company, someone to talk to’.

‘Make sure you have something to look forward to. Keep active and involved’.

Dear person with dementia...

“Life is for living’,
you’ve only got one life’.

Dear person with dementia...

‘Keep moving forward’.

Dear family and friends...

**Dear family
and friends...**

'I would be lost without
my family'.

Dear family and friends...

'It's good to still
have conversation'.

Dear family and friends...

'Help me to do the things
I can still do. Encourage me'.

Dear family and friends...

‘Involve me in decision making. I want to still feel needed’.

Dear family and friends...

‘Let’s talk together about my wishes for the future’.

Dear service provider...

Dear service
provider...

‘Accept me as I am,
my hands carry my history,
get to know me’.

Dear service provider...

Dear service provider...

'I still want a sense of meaning and purpose in life'.

'Being part of a group with like minded people is important to support a sense of belonging'.

Dear health worker...

Dear health
worker...

‘Treat me as an individual –
give me time, patience,
consideration’.

Dear health worker...

‘Communication is the key
for everybody to get to
know about me’.

Dear health worker...

‘Sometimes I get scared in
unfamiliar environments –
take time to talk with me,
reassure me’.

Dear all...

Dear all...

'Sometimes I can't find the words. I feel frustrated. I need patience, understanding, reassurance.'

Dear all...

‘Give me chance to think and speak for myself, otherwise I might stop trying to think’.

Dear all...

‘Don’t do things for us without discussing things with us’.

Dear all...

'I want to stay involved in activities. I still want to have fun'.

Dear all...

'I can still be creative'.

'I hate the loss of independence. I hate the loss of control of my own life. With the right support there are things I can still do'.

We are all different

We are all different...

I like singing

I like dancing

I like colouring

I like everything

I like doing things, making things, gardening

I like repairing

I like chocolate

I like going out dancing

I like walking my dog

I like loving my dog

I like being part of a group –

Sometimes it's the only way you meet other people

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