

Difficult Conversations

Making it easier to talk to people with dementia about the end of life

THE NATIONAL COUNCIL FOR PALLIATIVE CARE July 2011

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Compiled and written by Jo Black for NCPC, with a supportive foreword from Alistair Burns and acknowledgement for help from Joy Watkins and Karen Harrison Denning, both from Dementia UK, this is a booklet with pedigree.

Drawing (literally) on conversations with 50 people with dementia and their families, it addresses key dementia issues from the time of wondering, through the receipt of a diagnosis, the life that follows and on to the prospect and reality of death and beyond. That is a lot to cover in a small space. It is achieved by capturing real words in Snoopy, Charlie Brown and Lucy bubbles which cut through any fudge right to the core of what concerns people and what they want to know, need to know. The narrative text responds to these cues with pithy, apposite advice and guidance. Some of this you might feel is rather PC and confident while reality often strays from such safe ground. Yet this is generally a sound and useful reference resource.

You might feel a little angry with the suggestion: 'Have you tried an Admiral Nurse?' In most of the country this is an empty promise because, other than access to the national helpline, there is no Admiral Nursing Service despite John Suchet's high-profile two year old plea that every locality should have an effective cadre.

Specialist Palliative Care Nurses? How many areas can boast these? The impressive outreach pilot from St Christopher's showed the way but few have thus-far found the resource and determination to follow.

The references to advantages and fears arising from the use of syringe-drivers as death approaches in dementia will be puzzling for most families and professionals, for this is an option in very few places.

So the blessings which come with this latest gift from NCPC are mixed: High quality communication and support for families and professionals seeking to find peace in an important and hazardous area; but a mighty challenge to make better practices available more widely in the reality of the UK 2011 and hereafter.

We recommend that copies of this excellent booklet be available in every GP surgery, Memory Clinic, Community Mental Health Team for Older People, General Hospital Medical Ward and forward thinking hospice.

DJ and MT July 2011