



LAW REFORM
COMMISSION/COIMISIÚN UM
ATHCHÓIRIÚ AN DLÍ



Patient Preferences - a process based approach

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Hospice Friendly Hospitals Programme

The vision of the Irish Hospice Foundation

'No one should have to face death
or bereavement without
appropriate care and support.'

Informed by work of HfH Programme

- Three Aims
 - Standards Development
 - Capacity Development
 - Culture Change

- Four Themes
 - Integrated Care
 - Communication
 - Design & Dignity
 - Patient Autonomy

Feedback to the HfH Programme

- Concerns regarding the level at which decisions on resuscitation are made
- Concerns regarding the way in which decisions are made without consultation
- Frequently expressed concerns about the wishes of patients being ignored
- Avoidance of discussion on patient preferences by some care staff
- Some people's preference is not to engage in end of life related discussion
- Advanced Care Directives occasionally associated with euthanasia

'While advance directives are widely advocated for end-of-life decisions, they should be seen as **part of an overall process** that aims to adjust and improve the culture of end-of-life treatment and care for all parties concerned'

Is it Time for Advance Healthcare Directives?
The Irish Council for Bioethics 2007

Key Messages

Legislation is required to facilitate processes whereby citizens / patients can indicate their preferences for care and treatment and to establish their right to have these preferences respected



What is desirable is not always possible

What is possible is not always desirable

Approach

- Citizen / Patient
- Public Awareness & Understanding
- Preferences Change with Circumstance
- Enabling a Process

Citizen / Patient

A 'Life Events' Approach

'Take me out and shoot me'

The most common advanced care directive?

Public policy in Ireland, which seeks to plan for and address social needs based on a 'life events' approach, does not, at the moment, adequately address the wider experience of end of life.

Proposal for a Forum & Coalition
on End of Life Care

Irish Hospice Foundation 2008

Life Events

- Birth
- Childcare
- Education & training
- Employment
- Marriage
- Illness and / or disability
- Retirement & older age

- *Dying, death & bereavement*

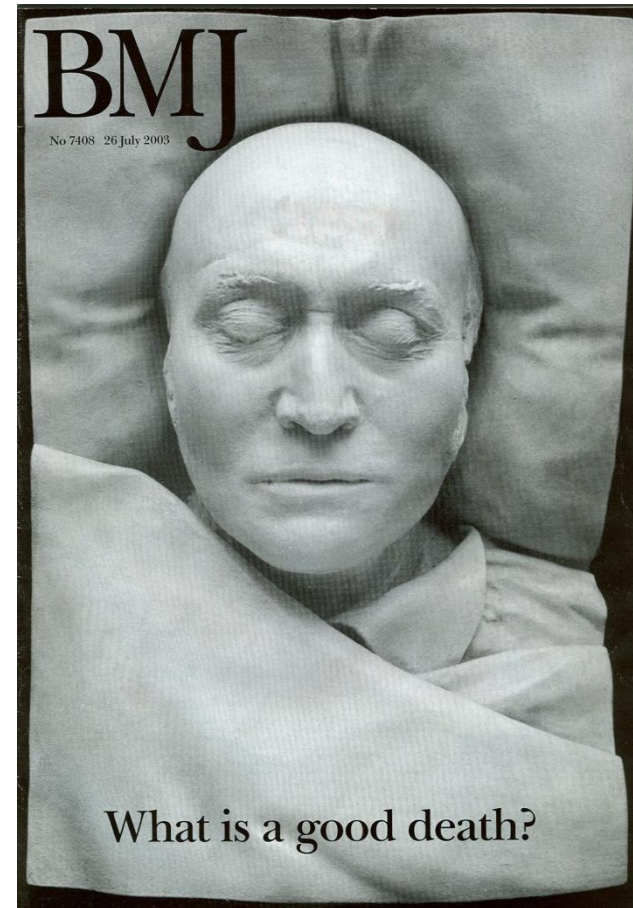
'.. emerging signs of public demand for the 'right' to a good death arising from concerns with the institutionalisation of death and disquiet about how people die'.

Ken Worpole

Writer & social commentator

`...a more educated and rights-conscious citizenry which has grown up in a consumer culture`.

More rights than the last rites

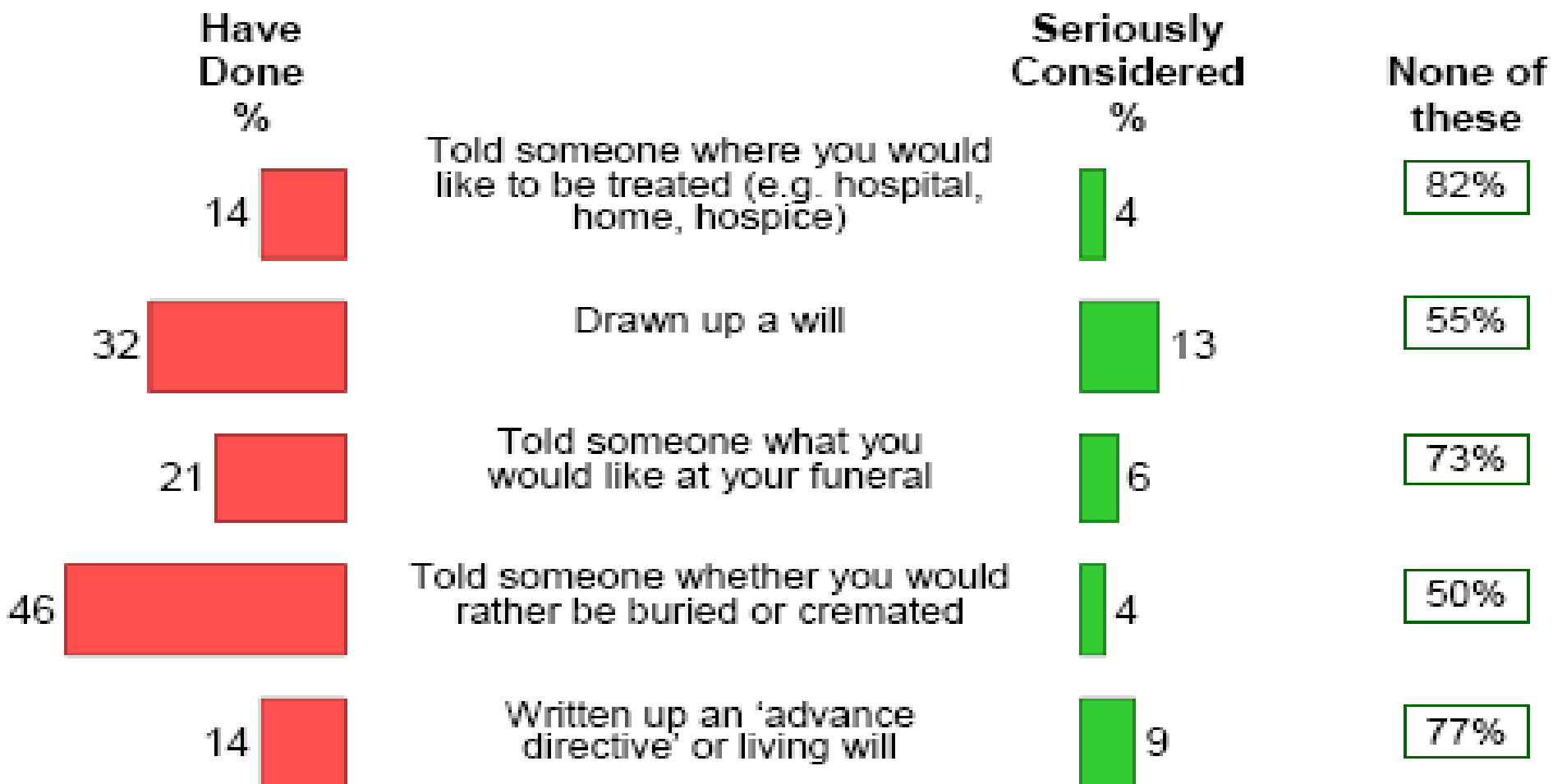


Citizen or Consumer ?

- Abstract view of person as absolute centre of decision making turns health care into consumer/commodity relationship
- Does not fit the reality of the dying person
- **Responsibilities as well as rights**

Arrangements in place – a responsibility?

Weafer & Associates & IHF 2004



'At present, the law is unclear about the status of any wishes expressed by the deceased and about who is entitled to make decisions in relation to, for example, the funeral service and burial or cremation'

Submission to the Law Reform Commission Public
Consultation on 3rd Law Reform Programme
Irish Hospice Foundation 2007

PATIENT INVOLVEMENT

'A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions that affect their lives...'

HeBE 2002

Patient Involvement (Goal 3)



National Strategy for Service User
Involvement in the Irish Health Service
2008-2013



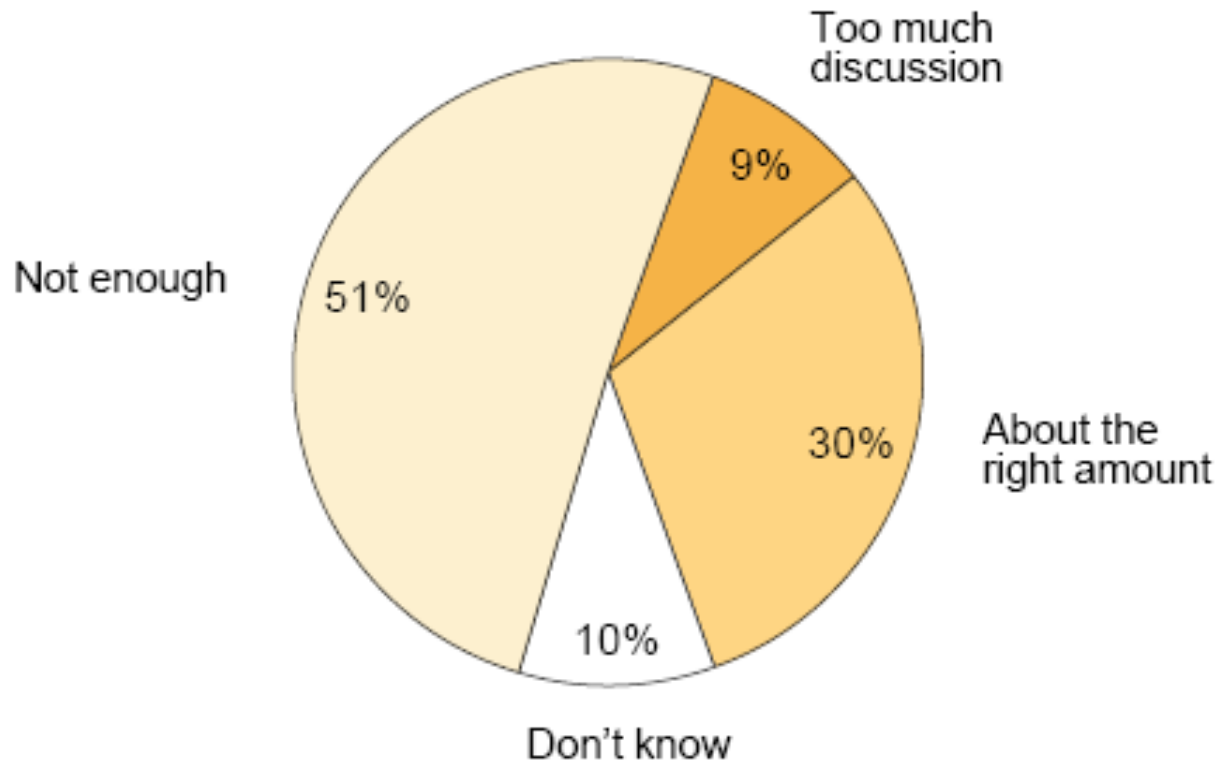
your service
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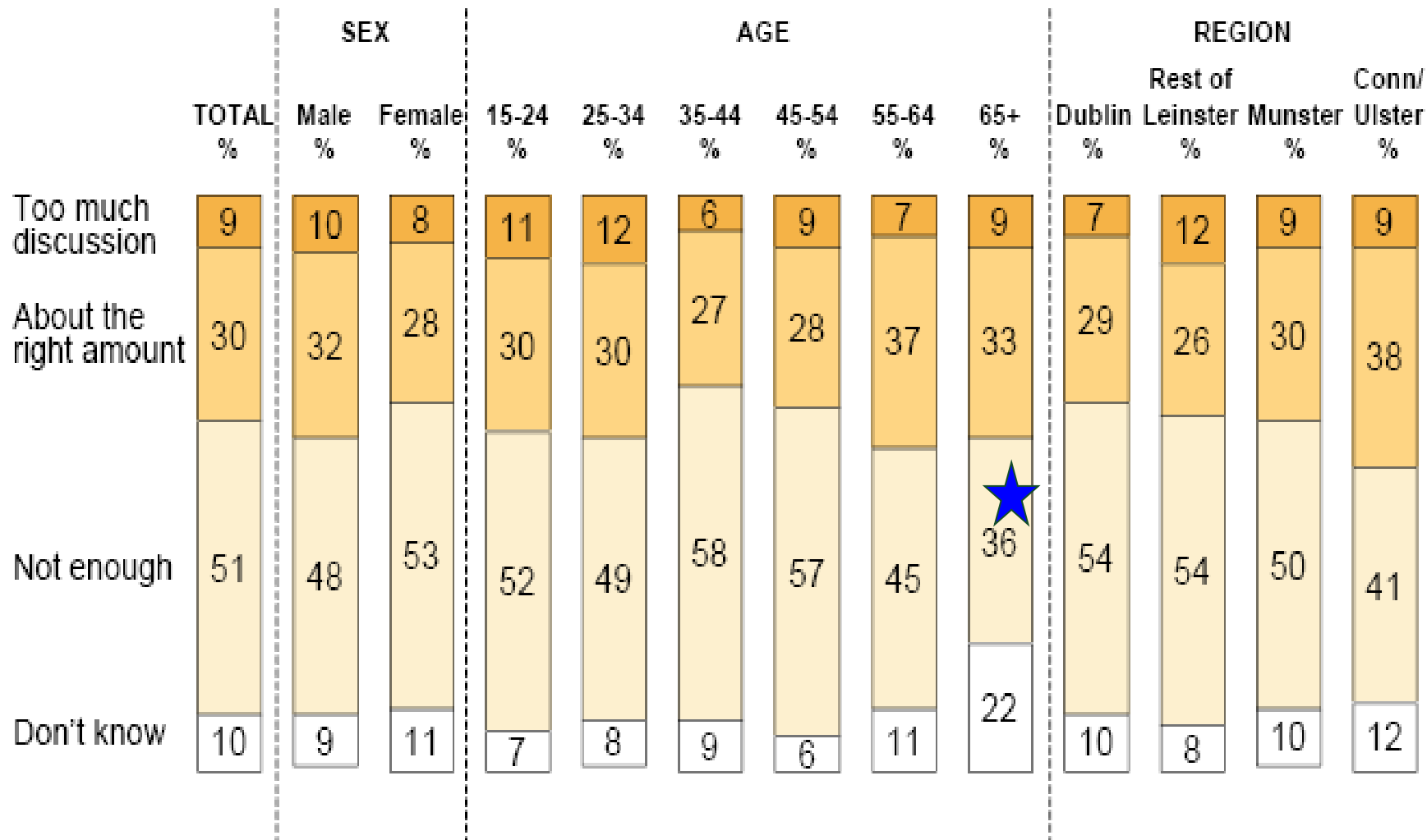
- The HSE will promote patient involvement in their own care as partners with health professional
- The HSE will educate staff in the importance of patient involvement in their care
- Service provision to service users with long-term illness will be specifically targeted to promote user involvement in care

Public Awareness & Understanding

Level of Discussion about Death & Dying in the Community

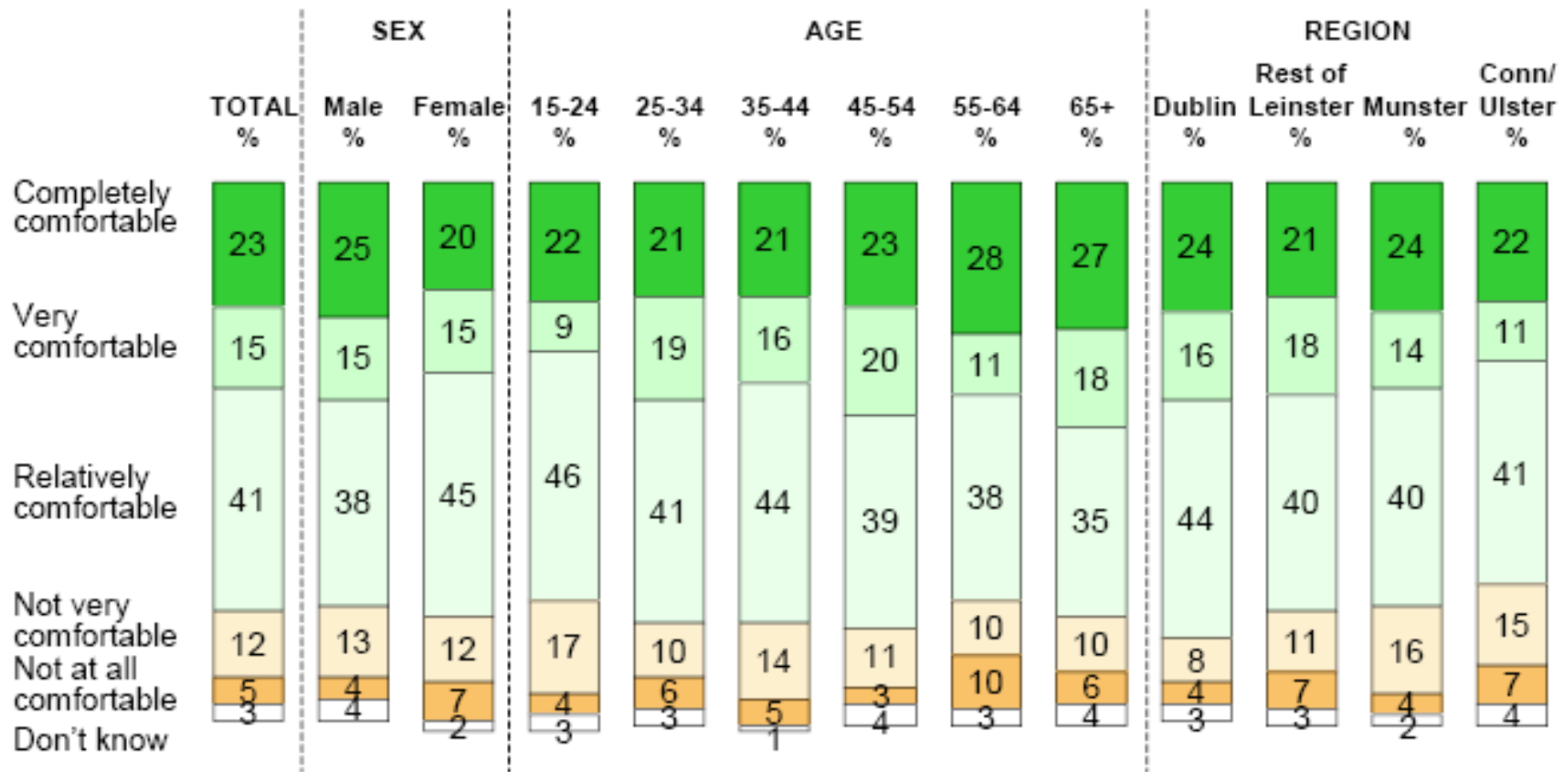
Weafer & Associates – Irish Hospice Foundation 2004





Q. Do you think that as a community, we discuss death and dying.....?

Comfort with discussing death & dying



Q. How comfortable are you personally with discussing death or dying?

Ethical Framework (UCC & RCSI)

Focus Groups & National Survey

Weafer & Associates & Irish Hospice Foundation (2007)

Aim: explore views about diverse end of life issues, especially those associated with patient autonomy

Two focus groups considered:

- Attitudes to death and dying
- Understanding of issues associated with death and dying
- Opportunities to express needs and preferences
- Findings contributed to development of questionnaire for national survey

Key Findings of Focus Groups

- There is a time and context for discussing death and it is clearly not a 'water cooler' moment
- Most people would discuss death following the death of someone they know but not on a social or casual basis

Profound Issue - Practical Consequences



Views of a Good Death

- **Fast and peaceful/ To die in your sleep.**
- To have your family with you when you die.
- To have control over the time and circumstances of your death.
- Cared for at home, with adequate medical support.
- No pain or suffering involved.
- To die with dignity and all that entails.
- Your children to be reared and independent.
- **When you are old; in accordance with the natural life-cycle.**
- With enough time to get your affairs in order.
- Emotional reassurance for the dying person.
- To stay alive as long as possible.
- To have time to do what you always wanted to do.
- **With a pint of Guinness in one hand and a model in the other!**

Standard view in end of life care:

- Right to refuse life-prolonging or burdensome treatment; right to privacy
- Obliges professionals not to interfere, overrule, intrude or breach confidences

Counters worries about authoritarian and paternalistic practices

- In general, respondents would like more control over their own deaths than for their loved ones. This is largely due to a perceived need to protect the sick person from unwanted stress
- However, although they would like to have more control over their final days, few would be willing to formalise their instructions too far in advance

National telephone survey (MRBI)

667 Respondents (adults 18+ years)

Focus of questions:

- Awareness of terms
- Disclosure of information
- Authority for decision-making
- Advance decision making
- Attitudes about dying
- Concerns about dying

QUESTIONNAIRE

Very often

Often

Sometimes

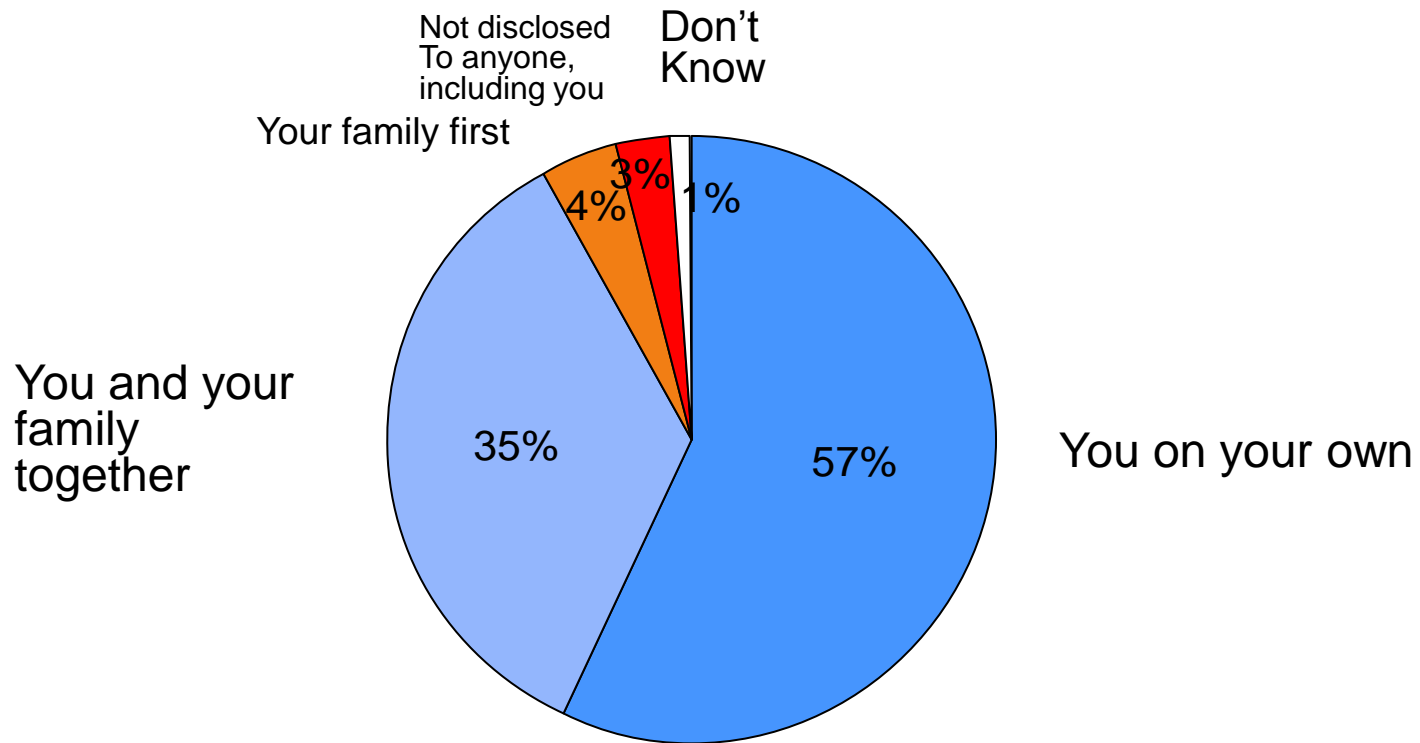
Rarely

Public Awareness of Terms

- Most people had never heard of the term 'Advance Directive'
 - 81% either 'never heard' or 'heard & knew nothing'
- 53% claimed to know something about the term 'Living Will'
- 61% claimed to know something about the term 'Do Not Resuscitate'

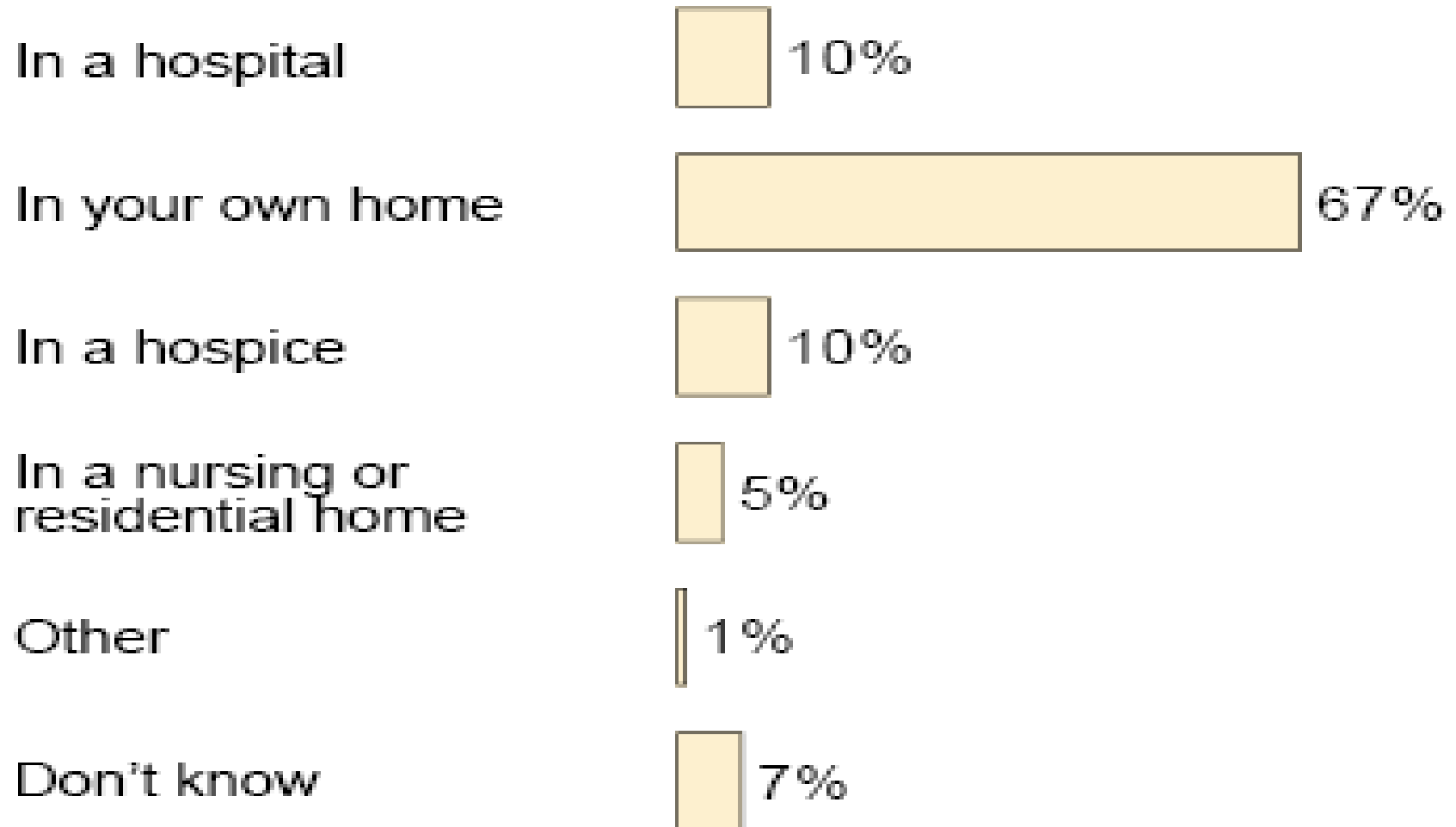
Disclosure of Terminal Illness

(Base: All Respondents, N = 667)



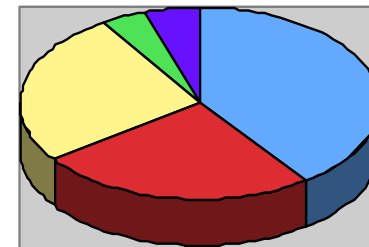
Preferences change with circumstances

Preferred place of care if dying



Location of Deaths

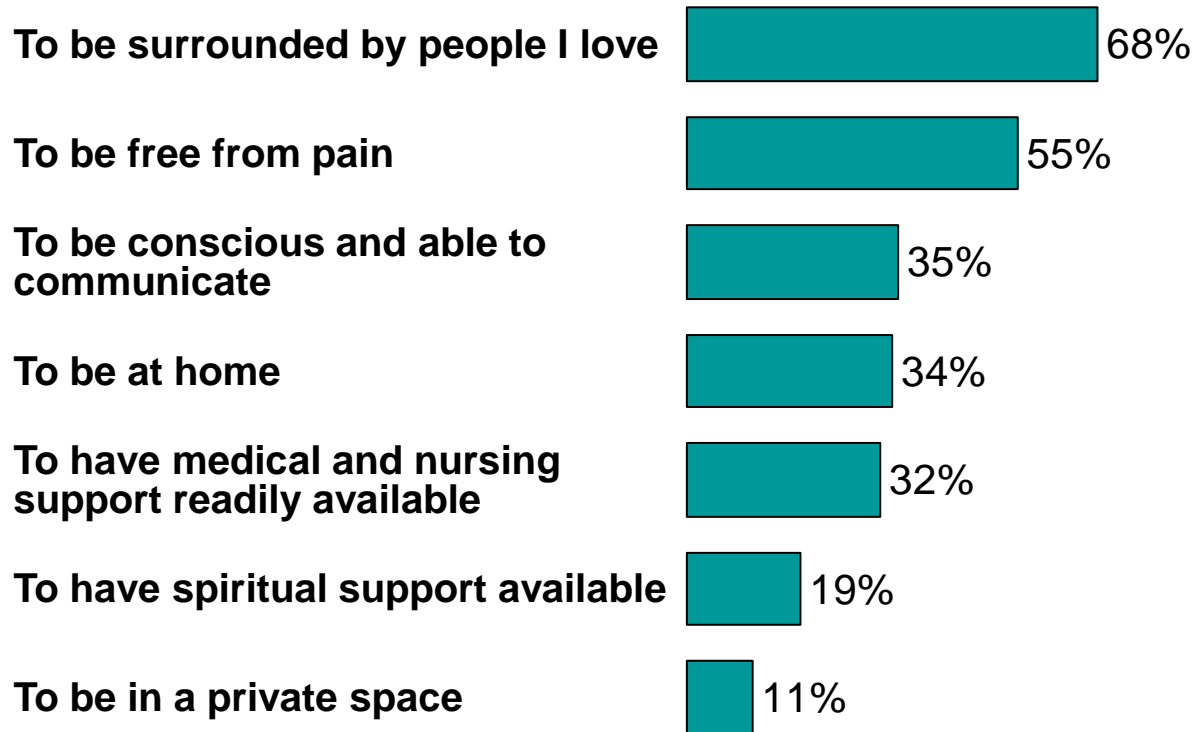
- **Home** **26%**
- **Outside Home** **74%**
 - Hospice 4%
 - Acute Hospital 40%
 - Long-Stay* 25%
- **Other*** **5%**



- Acute Hospital
- Long-Stay Facilities
- At Home
- Hospice
- Other

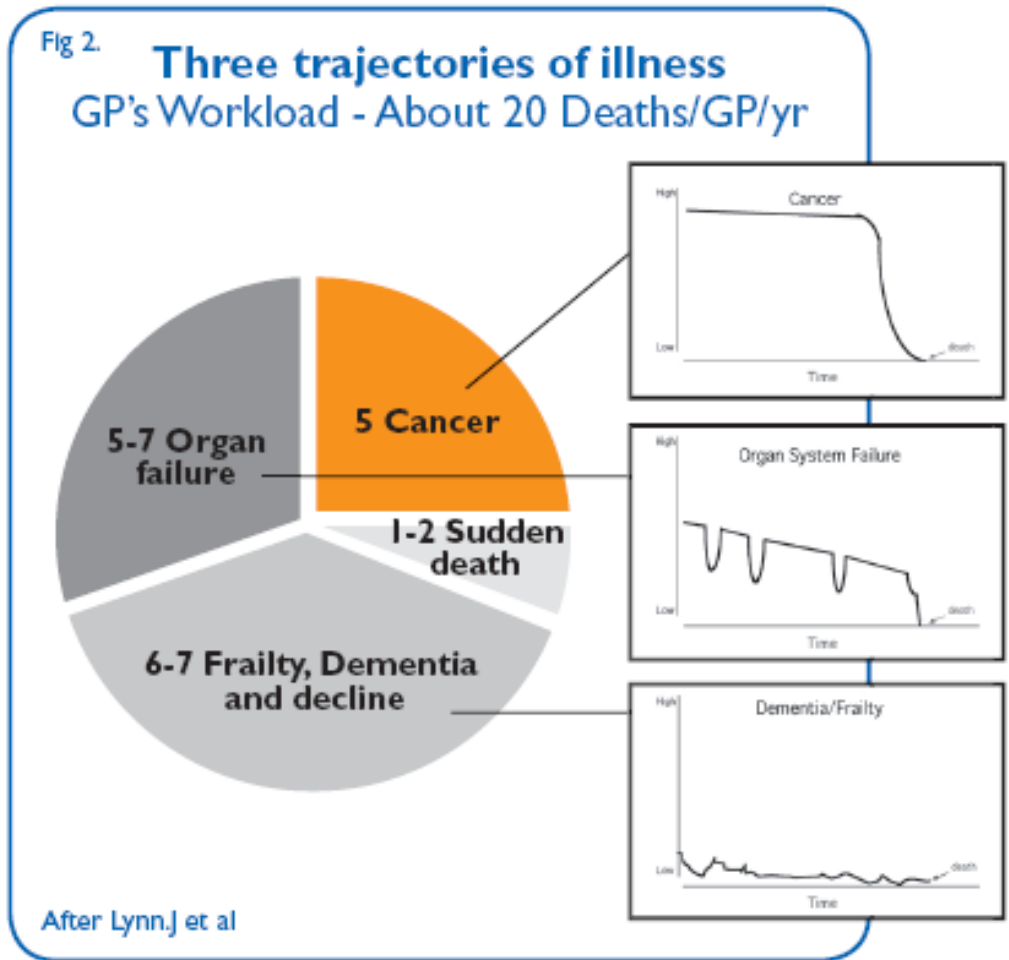
Most Important Things About Care Available to You if Dying or Terminally Ill

Base: All Respondents (n=1,000)



*Total exceeds 100% - Respondents selected up to 3 important things

Circumstances of dying differ



Enabling a Process

...for engaging with end of life issues

What is required?

- Public Education
- Systems & Resources
- Personal Advice & Guidance
- Communications Skills
- Privacy & Confidentiality
- Ethical framework – value of & limitations on autonomy
- Review Systems
- Legislation

Public Education

– positive or negative approach?

- **DNR**
Do Not Resuscitate
- **ADRT**
Advance Decision to Refuse Treatment
- **AND**
Allow Natural Dying
- **ACD**
Advance Care Directive



**Establishing
Preferences**

**BURIAL POST BURIAL &
REVIEW**

MORTUARY

DEATH

DYING PHASE

**TEST ASSESS TREAT
REVIEW**

ADMITTED

MEDICAL EXAM

INITIAL EXAM & ASSESMENT

ARRIVAL

PRE ARRIVAL & ACCESS

**Ongoing process
or
Once off event**

Registering & Accessing Preferences



Could an NGO develop a service?

FIVE WISHES[®]

MY WISH FOR:

1 The Person I Want to Make Care Decisions for Me When I Can't

2 The Kind of Medical Treatment I Want or Don't Want

3 How Comfortable I Want to Be

4 How I Want People to Treat Me

5 What I Want My Loved Ones to Know

print your name

birthdate

- Helps you express how you want to be treated if you are seriously ill and unable to speak for yourself
- It is unique among all other living will and health agent forms because it looks to all of a person's needs: **medical, personal, emotional and spiritual**
- Encourages discussing your wishes with your family and physician

Advance Decisions To Refuse Treatment - Mozilla Firefox

File Edit View History Bookmarks Tools Help

http://www.adrtnhs.co.uk/

Most Visited Customize Links Free Hotmail Windows Marketplace Windows Media Windows

Google Search PageRank Check AutoLink AutoFill Settings

ADRT ADVANCE DECISIONS TO REFUSE TREATMENT NHS

"Protecting Your Choice When It Matters"

HOME NEWS ABOUT US PUBLIC & PATIENTS HEALTH & SOCIAL CARE PROFESSIONAL CONTACT US

Welcome to the Advance Decisions To Refuse Treatment (ADRT) website

This site explains how the law now allows people to make decisions to refuse treatments including those that sustain life. Many people want to achieve a natural and dignified death, this is one way to help achieve it. This is a free and non-profit NHS website. We suggest people enter the site using the relevant menu section (above). Many people benefit from looking at both sections.

Before entering the site, please consider watching this short video **"It's All About People... It's ALL About Partnerships"** (see right) that tells a compelling story of Penny who has terminal illness and her right to make an ADRT, which outlines her future plans for treatment to help her achieve a natural death and with

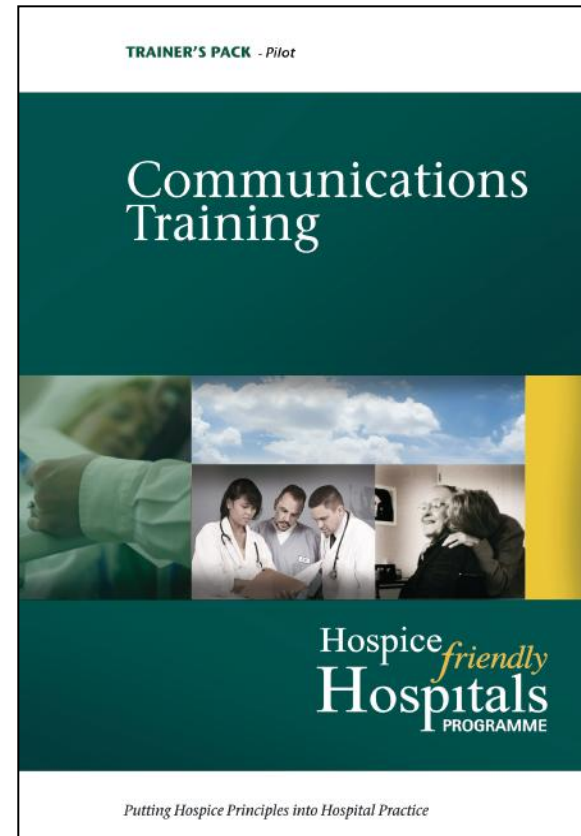
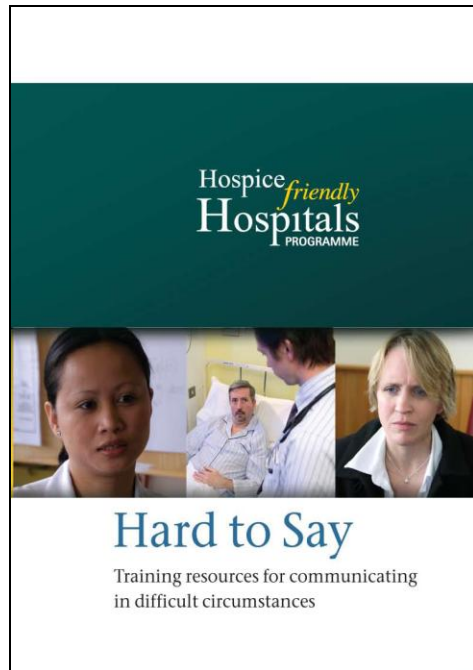
Latest News Updates

- [ADVANCE DECISIONS TO REFUSE TREATMENT - A Guide for Health and Social Care Professionals - 2008](#)
- [New ADRTNHS website launch Sept. 2008](#)
- [Finalists Health and Social Care Awards 2008](#)
- [New Technical Specifications / Help for the website](#)

Transferring data from www.adrtnhs.co.uk...

Start | Inbox - Microsoft... | Re: trolley cover... | Advance decision... | 2 Windows Expl... | Advance Decisi... | EN | 17:03

Communications Skills Training Essential



Initiating a conversation regarding end of life preferences is not easy for some staff



Privacy & Confidentiality Essential



Reviewing the Process

- National Audit of End of Life Care in Hospitals (Starting November 1st 2008)
- System for review & learning re deaths at ward/unit level
- Regular review of resuscitation practices and policies
- Engage with Oireachtas Committee on Health

Legislation

to facilitate processes whereby citizens / patients can indicate their preferences for care and treatment and to establish their right to have these preferences respected

Thank You