

**Difficult
Decisions**

Managing Conflict
Fairness

**Planning
Ahead**

Communication

*Utilitarian
Approach*

Challenges for practice

Education



RATIONING DECISIONS

*People
and
Populations*

Cost Containment

**Challenges
in Caring**

*Slicing the
Cake*

Human Rights

**Ethical
issues**

Moral Choices

Holistic Care

**Scarce
Resources**

Justice

Solidarity

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Imperfect

Ways

to

Slice

a

Cake



NHS 1948



- Cradle to Grave Care
- Free at the Point of Delivery
- National “Insurance” built on the Principle of Solidarity
- Effectively - State run Monopoly
- The Envy of the World

NHS 1948

- Rationing – to ensure equitable and fair distribution of scarce resources (war time)
- Organ transplantation still in this category
- Cost containment – ranges from good housekeeping to priority setting on to restricting potentially beneficial healthcare

Cost Containment

- Capping costs and staying within budget – a legal requirement for Health Boards
- Tends to be about short-term initiatives rather than long-term consequences
- Priority setting part of effective management
- Became a Euphemism for Rationing
- Rationing is one form of containing costs
- Others include eliminating waste; setting tariffs for services and drugs

People and Populations

- Priority-setting - decisions about the allocation of resources between the competing claims of different services, different patient groups or different elements of care
- Giving priority to service A when allocating resources does not tell us anything about whether individual patients in services B, C or D are deprived of potentially beneficial interventions or suffer a loss in the quality of care

Rationing

- Denial of potentially beneficial interventions or treatment
- Saving at the expense of quality, and quantity
- Tension between Governments' desire to control costs and the risk of Electoral Repercussions
- Implies limited supplies - “not enough to go round”
- Implies that not everyone will get what they might benefit from – marginal benefits?

Cents and Sensibility

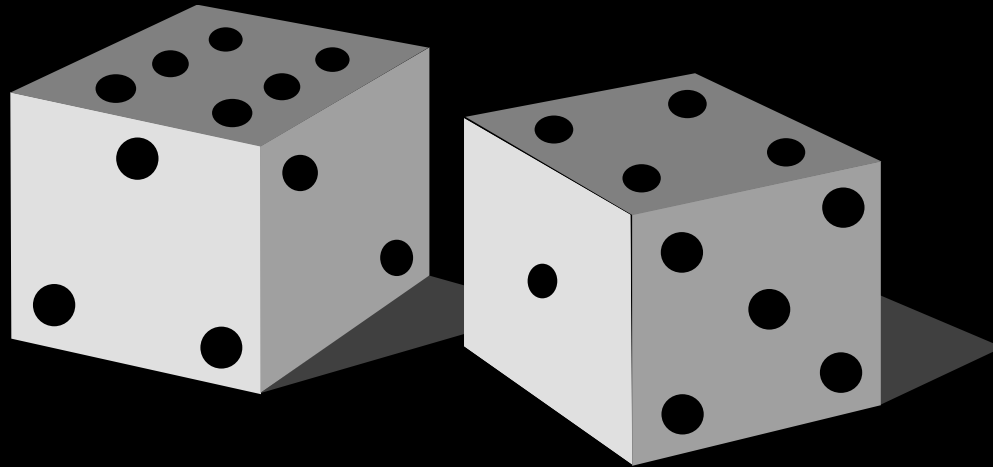
Is rationing inevitable?

- Why are resources limited?
- Is the budget realistic?
- Is demand unrealistic? – wants not needs
- Is the organisation working efficiently ,
appropriately and effectively?
- Invest to save - the Cost of Everything and the
Value of Nothing?

Rationing

- By denial - refusal to fund particular treatments (headline-catching)
- By selection - only for particular patients – criteria?
- By delay - the traditional Health Service waiting times
- By deterrence – patients and clinicians may be put off a service by obstacles to access
- By deflection - shunted off to another service or agency, or to specialist centre
- By dilution - quality of care and treatment declines as cuts are made to staff numbers, skill mix, available resources, investigations and technology

Risky business



People and Populations

Decisions on who gets what are taken at all levels:

- Government determines the overall budget for the NHS, against competing claims of other public services and the rest of the economy
- Health Directorate designs and applies the formula for distributing budget to Health Boards, who decide between competing priorities when allocating resources to specific services
- Local level involving the individual patient, and clinicians deciding how to allocate limited time and resources

People and Populations

Planning at population level:

- NHS Boards in Scotland, in common with healthcare organisations across the United Kingdom, have a duty to promote and provide for the health needs of the local population, while operating within financial, ethical and legal parameters.
- The health needs of the population change over time, as do the public's expectations of its health services and understanding of the measures that can improve health and prevent or treat disease.
- If resources available to the NHS are finite, it will necessitate tough choices over how the money is spent.

Rationing and population

Criteria vary with the level at which decisions are made:

- The further away decision making is from the individual patient, the more utilitarian principles are invoked: to maximise the health of the population as a whole
- The nearer decisions get to the patient, the more the traditional ethical criteria are invoked: the focus switches from populations to individuals.
- Where the two perspectives come together – when decisions based on seeking to maximise the health of the population have to be applied to individuals – there is most tension
- Across all levels in the hierarchy of decision-making, there is another tension - how decisions should be taken?

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Making Difficult Decisions

- The Oregon Plan was an attempt to increase population coverage by limiting the range of treatments on offer to people
- Used health economics to identify a ranked list of 587 services that would be provided by Medicaid.
- Arbitrary technical ranking not successful e.g. teeth capping was initially above appendicectomy ectopic pregnancy
- People with disability faced unfair treatment (based on concerns that including quality of life risked undervaluing the life of these patients)

Making Difficult Decisions

- Boards need to take account of national issues (legislation, judicial rulings, policy and targets), and local, including demographics, and the perspectives of patients, professionals and the public
- SIGN, SMC, and NICE issue guidance on decisions around new drugs and technologies
- With devolution, NHS Scotland and the rest of the UK now considerably diverged, but information and decisions are taken into account, although they may not correspond entirely
- The decisions of SMC on new drugs, and implementing SIGN or NICE guidelines, can have major implications for NHS Board budgets and local decision-making

Making Difficult Decisions

- Decisions about the treatment provided by an NHS Board or clinical service are determined by a range of influences (e.g., professional guidelines, and national and local protocols).
- There are times when decisions made at a population level may need to be reconsidered for an individual patient – where they become an “exceptional case”, or when established mechanisms have not yet considered whether the intervention in question should be made available on the NHS
- There needs to be a system for considering the treatment options for individual patients and for deciding, justifying and explaining when certain options are not supported.
(**ITR** – individual treatment request)

Rationing and population

- The National Institute for Health and Clinical Excellence (NICE) attempts to depoliticise decisions and to base them on expert evidence. However, its reliance on Quality Adjusted Life Years (QALYs) continues to be controversial, making NICE vulnerable to political pressure
- NICE acknowledges that social value judgements have to inform its decisions as quality adjusted life years are not considered sufficient, by themselves, for priority setting (£20-30,000)
- The NHS Constitution enshrines the right of patients ‘to drugs and treatments that have been recommended by NICE’

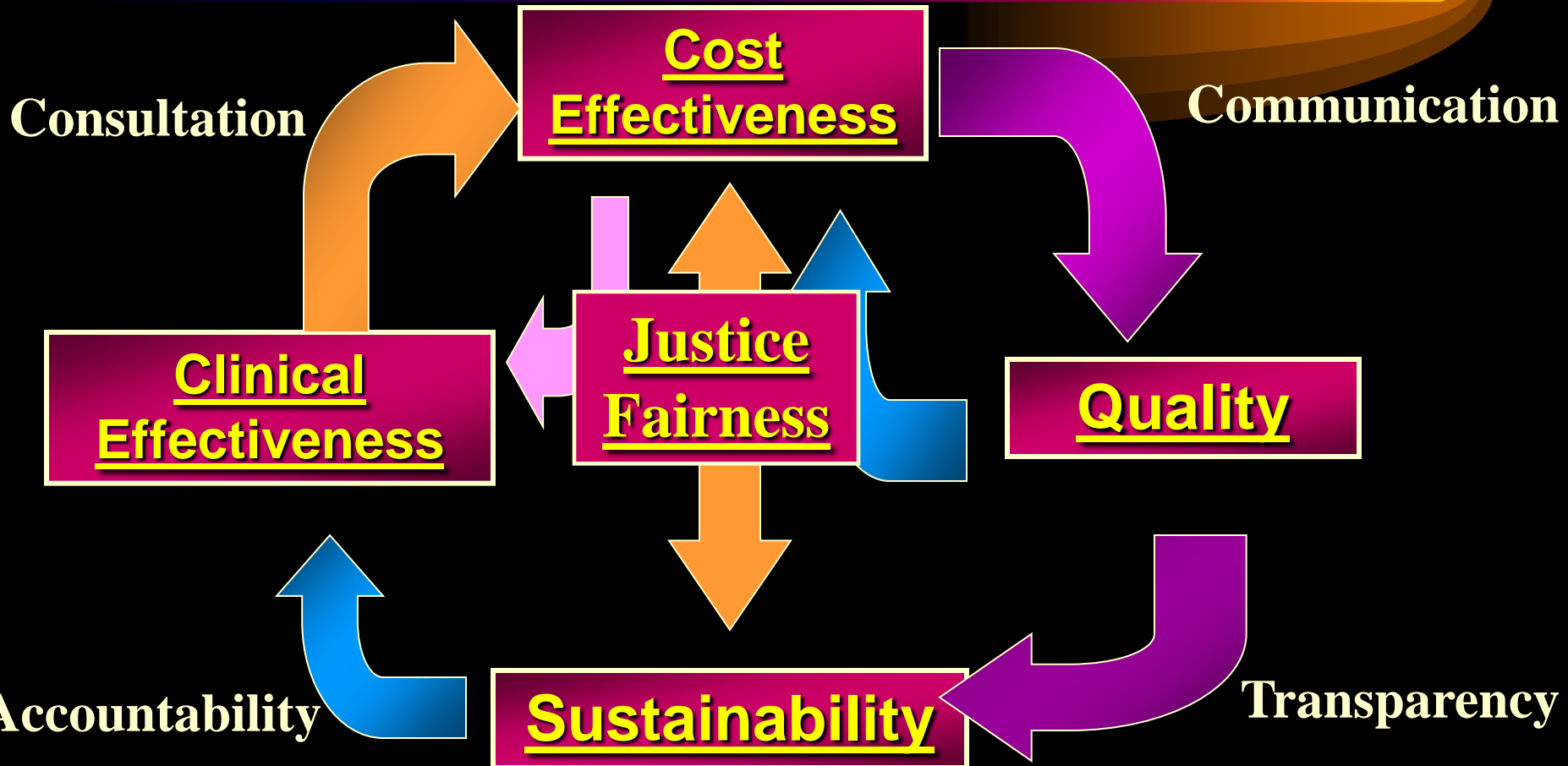
Difficult Decisions

- We live in an age of Self-determination and Human Rights.
- The Scottish Ministers are duty bound to promote a “comprehensive” health service. Decisions on allocation of resources can be challenged at the national, service or individual level, and these challenges take the form of a *judicial review* of the original decision-making process
- The grounds for such a challenge are limited to a few key arguments: illegality, irrationality and procedural impropriety. The traditional benchmark is whether a public authority (such as an NHS Board) has reached a decision which *no reasonable public authority* would have reached

Difficult Decisions

- The courts have been reluctant to direct a NHS Board on how to spend its money. They might rule that a particular policy or approach is illegal because it cannot be justified on grounds of reasonableness or logic. This means that the Board must revisit and revise its position so that it is not unreasonable or illogical; it does not necessarily follow that patients previously denied care will now be entitled to it
- The key concepts in law as it applies to decision-making in the NHS are *reasonableness*, *transparency*, *procedural fairness* and, ultimately, *accountability*.

Decision making



Difficult Decisions

- Communication
- Patient and Public Involvement
- Values/ principles
- Justice
- Quality, and clinical and cost effectiveness
- Transparency and Accountability
- Reasonable, consistent, comprehensive, justifiable
- Appeals process

Rationing and population

- There are increasing reports of rationing of cataract surgery and knee and hip replacements – often by combining selection criteria, and delay
- Outright denial of particular services or treatments within hospitals still seems to be relatively rare, though pressure is increasing to reduce follow-up appointments, consultant-to-consultant referrals and orders for diagnostic tests considered to be of marginal benefit
- Seemingly minor changes at the edges of services may have a cumulative effect resulting in rationing by dilution: a general diminution in the quality of care offered to patients

Additional Challenges

- When considering rationing, most attention is paid to quantity of care, and much less to quality
- Evidence of poor care being provided in poor environments to older people in particular (though not exclusively)
- Relationship between the level of resources and the quality of care is not straightforward, this would seem to be an example of rationing by dilution
- NICE (pushed by the government) decided that special value should be given to the last few months of life, especially as regards “cancer drugs”
- Should the same extra value not be attached to the last few months of life for older people in hospital? Why should drugs, as distinct from care, be privileged?

Additional Challenges

- The boundary between efficiency savings and service cuts is blurred: while efficiency savings mean (in theory) delivering the same service at less cost without any loss of quality, they can (in practice) mean cutting both quantity and quality.
- The most insidious, if also least visible, forms of rationing may well be the by-product of, or fall-out from, other policies as distinct from explicit decisions
- Cost Effectiveness Analysis does not consider the health gains forgone by reallocating resources from existing programmes to fund new programmes

Disinvestment

- This criticism is particularly relevant to NICE, as decisions on how to fund NICE's recommendations through disinvestments in other treatments are left to the local NHS trusts.
- NICE recommendations may not necessarily increase the overall efficiency of resource allocation decisions in the NHS, since it is possible that more efficient interventions (i.e. those generating more QALYs per pound spent) could be displaced in favour of the new technologies approved by NICE whose provision is mandatory

Additional Challenges

- Increasing emphasis on local decisions and local delivery for services – Post Code Lottery?
- Will Health Inequalities widen if accessing care depends on determination, persistence and political “savvy”?
- No decision about me without me – emphasises choice – fuels rising expectations?
- Public support decision making by professionals – but now wonder if cost drives decisions, and the doctor is a “double agent”

Additional Challenges



Is healthcare rationing inevitable?

- 2 approaches –
 - TINA
 - “There Is No Alternative”

MANAGING
CONFLICT



Peace...

Additional Challenges



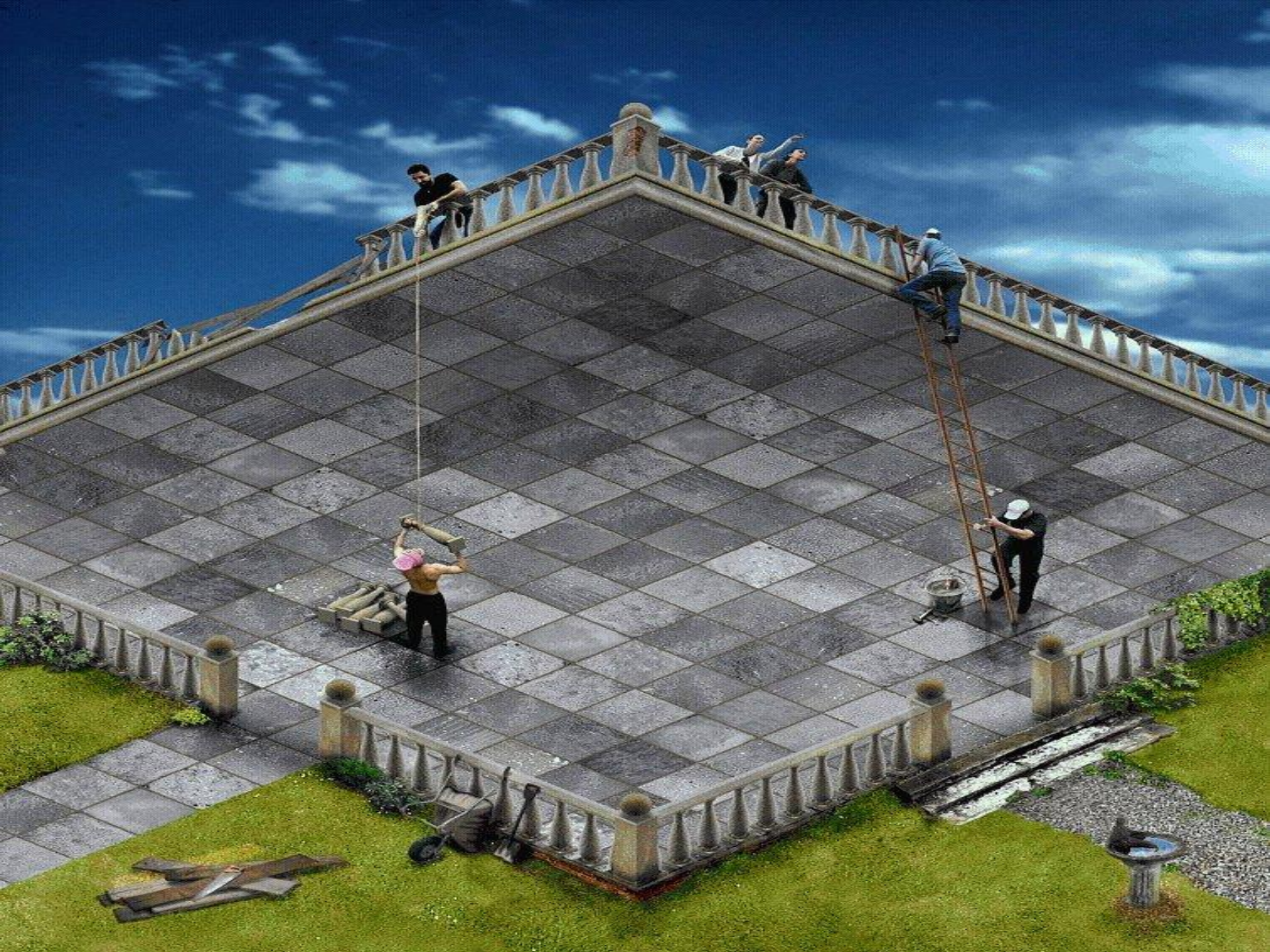
Or

- DORA –
- “Discover Other Realistic Answers”



Challenges for practice

- Rising expectations of healthcare
- Changes in demographics and disease
- Aging carers
- Split and dispersed families
- Single person households
- Constrained financial and professional resources
- Dys-economy of scale
- Austerity!



Challenges for practice



Service Delivery

and

Reaching the Many

Doing more with what we have?

Doing more with less?

Challenges for practice

- Austerity => cutbacks in funding
- Anxieties for Boards and Trustees => spending cuts
- Recruitment freeze, non-replacement
- Risk of losing most experienced nurses and consultants
- Loss of expert knowledge, experience, skills
- Compromise quality and standards



Challenges for practice

- Cost *versus* Cost-effectiveness
- Saving money *v* maintaining Quality
- Saving money *v* Clinical effectiveness
- Business model *v* Service model
- Excellence requires Good Leadership and Effective Management

Challenges for practice

- Can we build capacity by working differently?
- Temptation to limit overheads by reducing most expensive/costly parts of service without cost/benefits analysis
- What happens to quality and standards of care?
- Monitor and evaluate services for quality

Challenges for practice

- Challenge of caring for patients with whose underlying illness they are less familiar, and of working in different ways to meet their needs
- Allocation of funding and resources - Main providers of palliative care are out with the NHS based around hospices, which are charities, with limited financial support from the NHS

Challenges for practice

- Deploy Consultants more effectively
 - Extended Roles across the Multi-professional Team
 - Appropriate use of Scarce Resources
 - NOT a cutback – cost savings will need investment in training and education so a long term investment
- => Safe, Sustainable, Appropriate and Effective Services*

**Cup
Cakes
are
Easier
to
Divide**



Challenges for practice

- Advances in treatment and management mean that people are living longer with frailty, co-morbidities, and chronic conditions, and may develop more complex and burdensome symptoms
- All life limiting illnesses have implications for the physical, social, psychological and spiritual health of patients and their families

Challenges for practice



- Knowing what needs to be done
- Identifying what works and why
- Clinical excellence based on evidence
- Investing in people and education
- Reaching the many

Challenges for practice

Equity of Access

– needs based service must include:

- Socially Deprived (urban or rural)
- Mental health problems
- Drug and alcohol misusers
- Disabilities - learning, sensory, physical

Challenges for practice



- The Homeless
- Minority ethnic groups
- Prisoners
- Refugees and asylum seekers
- Travellers

Challenges for practice

- Carers and families
- Those with the wrong disease ... Stroke, Dementia
- Those who are living too long too slow to die
- The Frail Elderly

Which Part of

BUSY

Do you not
understand?!

Challenges for practice

- Holistic assessment of physical, social, emotional, cultural, religious and spiritual care needs and other relevant life circumstances
- Adequate alleviation of symptoms
- Acknowledgment of difficulties predicting outcome
- Emphasis on quality of life
- Support with difficult ethical issues

Challenges for practice

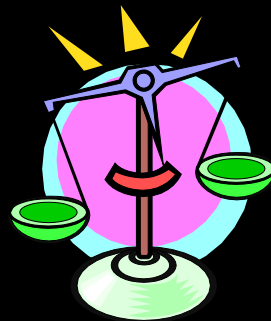
- Planning, co-ordination, but not necessarily delivery of appropriate care based on the needs identified
- Early discussion on prognosis/patient preferences
- Development of closer links with specialist teams
- Appropriate sharing and communication across all care settings of the needs and plans identified and actions taken
- Regular assessment and review of the goals of treatment



Patient values/choice

BEST
DECISION

Experience/
judgement/
knowledge




Evidence
based
practice

Challenges for practice

- Good practice and cost reduction by advance planning and reducing inappropriate admissions
- Population living longer with multiple long term co-existing conditions
- People are admitted to hospital more and more frequently in the last years of life, often on an emergency basis, and remain there for increasing lengths of time. Those in the final year of life accounted for around 30% of all bed days. (2011)

Challenges for practice

- Scarcity of palliative care resources will necessitate innovative ways of working
- Approximately 38,000 beds in care homes and 55,000 people over 65 years receiving home care (2011) A population of older people who may require palliation and support in these settings
- Palliative care services are finite. A change of emphasis towards shared care, with palliative care teams supporting the condition specific teams currently caring for patients seems the rational solution



I think there's a
spy among us...

Challenges for practice

- Build capacity by working differently
- Best use of experts within teams
- Effective communication between teams
- Advise, support, educate
- Learn from others

Avoiding the chaos

- **Who is involved?**
- **Who needs to be involved?**
- **Who is making the decisions?**
- **Where are they being recorded?**
- **Who is communicating with those who need to know – and how?**
- **How do we evaluate and develop evidence?**

Have a seat Kermit. What I'm about to tell you might come as big shock...



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Service delivery

- **Enthusiasm , good will, commitment and professionalism can only take us so far**
- **We can make these changes and embrace Excellence, and Equity of Care and Equity of Access but this will mean investment in people and resources**
- **We cannot grow and develop and deliver without that investment**

**“You matter because you are you
You matter to the last moment of your life
And we will do all we can
To help you
Not only to die peacefully
But also to live until you die”**

(Dame Cicely Saunders)







Equity - Excellence - Focus

An old man walked along the beach at dawn, and saw a young man ahead, picking up starfish, and throwing them into the sea.

On catching up, he asked him what he was doing, and was answered that the stranded starfish would die if left in the sun.

“But there are miles of beach, and millions of starfish,” countered the other. “How can your effort make any difference?”

The young man looked at the starfish in his hand, and threw it to safety in the waves, and replied:

“It makes a difference to this one.”