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effectiveness and cost effectiveness of many non-surgical treatments—such as self care, analgesia, anti-inflammatory drugs, and physiotherapy directed exercise—is lacking. We cannot assume that generic programmes are the best way to achieve changes in confidence, attitudes, and other psychosocial variables in all patients with osteoarthritis, or that such changes will be large enough to alter the future course of the disease. The government is committed to increasing the number of places on the expert patient programme, which is similar to the challenging arthritis programme, from the current capacity of 12 000 to

100 000 by 2012. The growing body of evidence about self management programmes stresses the need to question whether this policy will achieve its desired outcomes, namely long term gains in health coupled with reduced use of healthcare services.

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1 Jinks C, Jordan K, Croft P. Measuring the population impact of knee pain and disability with the Western Ontario and McMaster universities osteoarthritis index (WOMAC). *Pain* 2002;100:55-64.
 2 Hootman JM, Helmick CG. Projections of US prevalence of arthritis and associated activity limitations. *Arthritis Rheum* 2006;54:226-9.
 3 Buszewicz M, Rait G, Griffin M, Nazareth I, Patel A, Atkinson A, et al. Self management of arthritis in primary care: randomised controlled trial. *BMJ* 2006 doi: 10.1136/bmj.38965.375718.80.
 4 Ettinger WH, Burns R, Messier SP, Applegate W, Rejeski WJ, Morgan T, et al. A randomised controlled trial comparing aerobic exercise and resist-

ance exercise with a health education program in older adults with knee osteoarthritis. *JAMA* 1997;277:25-31.
 5 Van Baar ME, Dekker J, Oostendorp RAB, Bijl D, Voorn Th B, Bijlsma JW. Effectiveness of exercise in patients with osteoarthritis of hip or knee: nine months follow up. *Ann Rheum Dis* 2001;60:1123-30.
 6 Picavet HS, Vlaeyen JW, Schouten JS. Pain catastrophising and kinesiophobia: predictors of chronic low back pain. *Am J Epidemiol* 2002;156:1028-34.
 doi 10.1136/bmj.39013.359282.80

Advance care planning in primary care

Uncomfortable, but likely to engender hope rather than dispel it

Of the various trajectories of physical decline, organ failure is often the most difficult to plan for in advance because of its unpredictability.¹ The qualitative study by Davison and Simpson in this week's *BMJ* challenges the notion that early discussion of planning for the end of life will destroy hope rather than create it. Rather, it allowed patients dying of end stage renal failure and their carers to reflect on and reorient their aspirations.² A wealth of evidence indicates that many elderly patients want to discuss these issues with their healthcare professionals, but this rarely happens even when (as in the United Kingdom) continuity of care with a trusted general practitioner is available.^{3,4} The main barrier is probably doctors' reluctance to raise the issue of planning for death because of the largely unfounded fear of destroying hope.

Advance care planning is practised in Australia, Canada, and the United States.⁵⁻⁷ It is also proposed as a cornerstone of the emerging National Health Service national end of life care strategy in England (<http://eolc.cbcl.co.uk/eolc>). It should enable provision of services in accordance with patients' wishes—for example, patients choosing home care rather than other places.⁸

Advance care planning is now defined as a process of discussion between a patient and professional carer, which sometimes includes family and friends. This dialogue has two outcomes—an “advance statement,” which describes the patient's positive preferences and aims for future care; and an “advance decision,” which provides informed consent for refusal of specific treatment if the patient is not competent to make such a decision in the future. The last of these outcomes is especially relevant as the new Mental Capacity Act in England is due to be enacted in April 2007.⁹ The focus of advance care planning is thus shifting from

eliciting refusal of treatment from a minority of patients to identifying the preferences for care of most patients.

Internationally, advance care planning can be incorporated into primary care. In the UK this year, the new general practice contract has established practice based patient registers, including one for people who might benefit from supportive or palliative care and who might die within the next 12 months. Guidance has been developed through the Gold Standards

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Advance care planning: five point plan for primary care

- (1) Identify patients who may be in their last 12 months of life and add them to the practice's palliative care register
- (2) Assess their current health and social needs
- (3) Sensitive raise the following points with patients and their family or carers

What elements of care are important to you and what would you like to happen? What would you not wish to happen? Do you have a person who is willing to be a proxy or have lasting power of attorney?

If your condition deteriorates, where would you like to be cared for (first and second choices)?

Have you any other special preferences, requests, or comments?

Do you have a view on resuscitation if your heart suddenly stops?

These preferences should then be communicated to other services

- (4) Provide proactive personalised care and review this regularly with the patient and family or carers
- (5) If patients do not want a specific treatment should incapacity arise, seek specialist help to initiate a legal “advance decision”

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Framework programme (which is now used by over a third of UK practices) to identify and care for such patients.^{10 11} The box shows a possible scheme to use advance care planning to improve end of life care.

Realistic information, sensitively provided, helps patients and their families to maintain a feeling of normality and allows them to develop new coping strategies. Such discussions engender hope. Such hope is not for a cure but for understanding the process of dying and for reassurance that support will be given during a variety of eventualities. Calman described quality of life in terms of the gap between patients' expectations and reality.¹² Our role may be to negotiate realistic changes in expectation (by discussing likely trajectories, prognosis, and advance care planning) and concurrent improvements in reality (with good symptom control and support services) to improve quality of life in the final months and weeks.

Davison and Simpson's study is a small but important step in enhancing our understanding of the importance of notions of hope, even when to the outsider it seems that all hope is lost. Their findings need to be confirmed in other populations (the patients

studied were almost exclusively white) and through implementation studies to evaluate how best the proactive approach improves outcomes of patients. That said, considerable evidence supports the integration of advance care planning into routine practice as part of good care for all people with progressive life threatening illnesses. Planning for death with our patients may be an uncomfortable concept but is likely to engender hope rather than dispel it.

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- 1 Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330:1007-11.
- 2 Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* doi: 10.1136/bmj.38965.626250.55.
- 3 Sanders C, Seymour J, Clarke A, Gott M, Welton M. Development of a peer education programme for advance end of life care planning. *Int J Palliative Nurs* 2006;12:214-23.
- 4 Help the Aged. *Planning for choice in end of life care*. London: Help the Aged, 2006. www.helptheaged.org.uk/NR/rdonlyres/6C50EADE-2AB7-4025-9368-6787B5A23F08/0/planning_for_choice_in_endoflife.pdf (accessed 13 Oct 2006).
- 5 Hunter New England NSW Health. *Advance care planning*. www.hnehealth.nsw.gov.au/advanced_care_planning (accessed 13 Oct 2006).
- 6 Fraser Health. *Advance care planning. Let's talk*. www.fraserhealth.ca/HealthInfo/AdvanceCarePlanning/Default.htm (accessed 13 Oct 2006).

- 7 National Hospice and Palliative Care Organisation. *Advance care planning*. www.caringinfo.org/i4a/pages/index.cfm?pageid=3278 (accessed 13 Oct 2006).
 - 8 Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515-21.
 - 9 Department of Health. *The Mental Capacity Act*. London: DoH, 2005. www.dh.gov.uk/PublicationsAndStatistics/Bulletins/ChiefExecutiveBulletin/ChiefExecutiveBulletinArticle/fs/en?CONTENT_ID=4108436&chk=z0Ds8/ (accessed 13 Oct 2006).
 - 10 Department of Health. *The gold standards framework*. London: DoH, 2005. www.goldstandardsframework.nhs.uk/gp_contract.php (accessed 13 Oct 2006).
 - 11 Thomas K. *Caring for the dying at home. Companions on a journey*. Oxford: Radcliffe Medical Press, 2003.
 - 12 Calman KC. Quality of life in cancer patients—an hypothesis. *J Med Ethics* 1984;10:124-7.
- doi 10.1136/bmj.39009.569861.80

Age related macular degeneration

Better tools are needed to measure quality of life and visual outcomes

Wet (also known as neovascular or exudative) age related macular degeneration is a common condition of poorly understood aetiology that affects around two million elderly people in Europe.¹ In the United Kingdom, in about a quarter of a million people wet macular degeneration causes bilateral visual impairment of sufficient severity that they are registered as partially sighted or blind.² If only one eye is affected the onset of disease may go unnoticed by the patient. Wet macular degeneration is usually bilateral though, and when the second eye becomes affected the impact on the patient is devastating.³

Good vision is often taken for granted. It is an important prerequisite for a socially fulfilling and active lifestyle. Wet macular degeneration affecting both eyes has serious consequences for quality of life. The psychosocial and functional impact of sight loss due to this condition is reviewed in a paper by Mitchell and Bradley commissioned by the International Age Related Macular Degeneration Alliance.⁴ A

major problem is defining quality of life; this is highlighted by the lack of consensus in various questionnaires that aim to measure it.⁵ Mitchell and Bradley question the relevance of current instruments used to monitor health status, quality of life, and visual functioning in patients with age related macular degeneration. This is supported by the fact that popular instruments for measuring health status—such as the medical outcomes study short form 36 (SF-36), health utilities index 3 (HUI3), and EuroQol (EQ-5D)—do not capture the effects of sight loss on quality of life.⁴

Many people with neovascular macular degeneration report excellent health, either because the disease affects only one eye or they do not perceive sight loss as a decline in their general health status. Despite this, they are shocked by how rapidly loss of sight progresses and frightened at the thought of going blind and thus losing their independence, features that are not captured by existing instruments for measuring health status. Even when these instruments are used in