

requires communication skills and experience. It is best done by the person who has already established rapport and understanding with the parents. In most cases this will be a consultant clinician, but often a midwife, nurse, junior doctor, family doctor, or religious minister may have established a close relationship with the parents and this aids communication.

Secondly, many parents erroneously consider the post-mortem examination to be solely for research and linked with the notion of "donating the body for science." Informed discussion is needed about how an examination might be helpful. In truth, a fine line sometimes exists between the true benefits for the parents and the broader and indirect benefit to other babies. If this is the case then it must be acknowledged. Confusing the issue is a recipe for creating guilt on both sides, whereas a scrupulously honest approach is often rewarded by a genuine desire of parents to see their baby's death as in some way helping others.

Thirdly, those seeking consent must be prepared to answer questions about how the body will appear after the post-mortem examination has been completed. The notion of "suffering" may in fact be based on an erroneous perception that the body will be damaged beyond recognition before the burial or cremation.

Fourthly, if this fear cannot be alleviated by discussion it is often possible to obtain permission for a "limited" post-mortem examination and the advice of the pathologist should

be sought. The idea of damage to the head may underlie refusal to give consent, and one might negotiate consent to an examination that specifically excludes examination of the intracranial contents. This is useful when, for example, there are specific pointers towards congenital heart disease or liver or kidney disorders. Information can also be obtained from needle biopsy of organs. If there is a suspicion of dysmorphism then examination of the body by a clinical geneticist is important, and this can be supplemented by blood sampling or skin biopsy for chromosome analysis and a radiological skeletal survey. Valuable bacteriological, biochemical, and toxicological information can be obtained by examination of appropriate body fluids. Finally, the placenta should not be neglected as an important source of information.

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Shared care in diabetes

Better evaluation is needed

Interest is increasing in the greater integration of primary and secondary health care,¹ and purchasers are exerting pressure to shift patients from secondary to primary care, partly for financial reasons and often regardless of effectiveness. Examples of such integration in managing chronic diseases are schemes of "shared" or "integrated" care—for example, for patients with diabetes, asthma, or hypertension. Such schemes are loosely characterised by joint participation of hospital consultants and general practitioners in the planned delivery of care and an enhanced exchange of information over and above routine discharge and referral letters.²

Despite the growing enthusiasm for these schemes, they have not yet received sufficient critical evaluation to justify national adoption. This has been recognised by the NHS research and development initiative, which has identified shared care as a priority area for research.

Most research attention has been devoted to shared care for patients with diabetes, and this has recently been the subject of an extensive literature review.³ This review identified five randomised controlled trials and several other comparative, longitudinal, and descriptive accounts of shared care. In none of the randomised controlled trials does shared care improve the clinical outcomes, compared with hospital care and in two of the studies where care was less structured it was associated with poorer care or outcomes. These findings are in line with those of an earlier review.⁴

Given the contradictory evidence on this topic and the importance of ensuring that policy is based on reliable evidence for research,⁵ shared care obviously needs further evaluation before it is widely adopted. In addition we need much better methods for evaluating different forms of care if the results are to provide useful and reliable information.

Even though the most reliable way of comparing the effectiveness of shared care with that of hospital based care is by performing a randomised controlled trial, the existing trials are hard to interpret for two reasons. Integrated care is used as a "black box," which has a different content in different studies. For example, this may vary from giving a general practitioner a protocol to patient held shared care record cards and a range of responsibility for decision making from the hospital, primary care professionals, and patients. Until we have clearer definitions of the key features of a programme of shared care,² evaluations will be of limited use, not least because those aspects of shared care that might be important in influencing process and outcome will remain unclear. Once the content of shared care is more clearly defined then trials can be set up to compare the efficacy of different elements of a scheme. A good example is the 2×2×2 design used by the Grampian asthma study of integrated cases, which allowed comparison of levels of education, use of peak flow self monitoring, and integrated versus conventional care.⁶ Such trial designs will provide more insight into which features should be incorporated into an optimal shared care programme and possibly codified in practice guidelines.

The results of studies may be difficult to interpret and generalise from because the studies used shared care schemes that either predated the study or were set up in volunteer practices, likely to be run by more enthusiastic professionals (who might achieve better results⁷). Such biases are important to assess so that, for example, doctors who are more interested in other clinical issues are not forced to deliver what might be poorer care on the basis of unrepresentative trials. It might be that the optimal policy is to let general practitioners decide in collaboration with their patients what scheme of

care they prefer to administer rather than to impose a unitary system. This is particularly important given that almost 90% of general practitioners have been approved to run chronic disease management programmes for diabetes under the new contract.⁸

Glycaemic control is the most common outcome measured in diabetes care, which is justifiable given that the diabetes control and complications trial showed that good glycaemic control delayed the onset and slowed the progression of diabetes related complications.⁹ Nevertheless, glycaemic control incompletely measures quality of care because tight control increases the risk of hypoglycaemia.¹⁰ Efforts to improve control may also upset some patients as it usually entails a more demanding regimen. Both of these factors can seriously affect patients' quality of life. Evaluations of shared care should therefore incorporate outcome measures of importance to patients. The St Vincent's Declaration recognises that psychological factors are important, and guidelines for promoting patients' psychological wellbeing have been published¹¹ and several measures are now available.¹²

As glycaemic control and quality of life often conflict over the short and long term, patients' preferences become of paramount importance in determining the optimal type of care. Because patients' preferences may affect outcomes—for example, by influencing compliance and other behaviour—they need to be taken into consideration in the design of evaluative trials.¹³ A simple answer to the question of whether shared care is cost effective or even clinically effective is unlikely, not least because optimal care might differ between patients and practitioners. Shared care is not a panacea and its effectiveness and cost effectiveness are uncertain. We need

trials that take into account the complexities and interactions of setting, provider interest, and consumer preference.

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Primary orthostatic tremor

Causes difficulty in standing still

Heilman described the clinical features of primary orthostatic tremor 10 years ago.¹ Subsequent studies have elucidated the specific neurophysiological features of the condition, which clearly distinguish it from other tremulous disorders of the legs.²⁻⁴ Although the condition is rare, the incidence of this recently described condition remains unknown. Identification of cases is still increasing, with wider recognition of the characteristic clinical symptoms. Doctors should be aware of the typical symptom complex of orthostatic tremor, as many patients are wrongly labelled as suffering from psychiatric symptoms.⁵

The most prominent and characteristic symptom reported by patients with primary orthostatic tremor is unsteadiness when standing still—for example, at supermarket check outs or bus stops. By contrast, patients have little or no difficulty in walking, which typically relieves their symptoms.^{3,4} Despite the condition's name few patients complain specifically of tremor. Examination, when the patient attempts to stand still, reveals a fine rippling of the muscles of the legs that may be easier to feel than to see. After a short interval, the patient becomes increasingly unsteady and is forced to take a step to regain balance. Falls and injuries, however, are rare.

The diagnosis is confirmed neurophysiologically.²⁻⁴ Surface electromyographic recordings show rhythmic activation of lower limb muscles at a frequency of 14-18 Hz. Within any individual patient, the frequency is the same in all muscles and fixed. This frequency of muscle activity is characteristic of the condition and is much higher than can be produced

voluntarily and higher than that seen in other tremulous conditions (for example, essential tremor or Parkinson's disease, in which the frequency usually lies between 3 and 8 Hz⁶). Interestingly, rhythmic activation of upper limb muscles at the same frequency can be seen if patients use their arms to maintain posture—for example, by standing on all fours.^{3,4,7}

The cause of the condition is unknown. The neurophysiological abnormalities suggest a brain stem disturbance, and recent positron emission tomography studies have shown increased activity in the cerebellum in comparison with controls when patients hold their arms outstretched (which in some patients also brings out a tremor).⁸ Results on radiological examination are normal, and no other disturbance of brain stem function has been associated with the condition. The relation of primary orthostatic tremor to essential tremor is disputed.^{3,4,9} The condition affects both sexes and the age of onset is usually in the sixth or seventh decade of life, although it may begin as early as the third decade. Some patients have had symptoms for more than 20 years.

Although no specific treatment currently exists, patients are often relieved to know the diagnosis, particularly if a psychiatric cause had previously been suspected. Clonazepam,^{1,4,7,9} phenobarbitone,^{4,7} primidone,^{4,9,10} and sodium valproate⁴ have been used with occasional success. β Blockers and alcohol are ineffective. Stools (in the kitchen) and shooting sticks with rubber ends (for bus queues) may be helpful. With a better understanding of the condition more