

Communicating ethics

'First do no harm' is a well-known phrase, but it is only one of many guiding ethical principles we need to juggle as healthcare professionals. With the help of a hypothetical client with profound cognitive and physical disabilities, **Jois Stansfield** and **Jane Handley** explore how an ethical framework can help speech and language therapists and students negotiate a path to what feels like the 'right' outcome for a given situation at a given time.

READ THIS IF YOU WANT TO

- IDENTIFY YOUR OPTIONS
- UNDERSTAND DIFFERING PRIORITIES
- IMPROVE YOUR DECISION-MAKING

1. A tutor's tale – Jois Stansfield

Speech and language therapy students are routinely confronted with practical clinical issues during their pre-registration education. In some clinical areas, the 'right' actions appear to be obvious to students: for example, in many aspects of dysphagia management, the need to ensure nutrition and hydration can lead inevitably to the technical interventions necessary to maintain life. On other occasions students (and therapists) report feeling guilty because they sense they have not done everything they believe they could, but are not able easily to articulate the reasons for this, or to identify any ways in which they could have changed their decisions or actions.

Final year speech and language therapy students at Manchester Metropolitan University follow a case-based approach to ethical reasoning. They collaborate in workshops, identifying ethical issues involved in a range of hypothetical cases, and complete a piece of coursework based on one of these cases. Students are presented with a number of different ethical decision-making tools. One which they have consistently found to be valuable is the Seedhouse grid (Seedhouse, 2007). It enables students (and others) to identify elements of a case at different levels of decision making, and to judge the most important considerations with a given client at a given time.

Seedhouse has also developed an online approach to ethical decision-making, 'Values Exchange' (Seedhouse, 2005; www.values-exchange.com). It is an apparently simple, but challenging, method of enabling us all to make initial decisions, see others' ideas and reconsider our own views, with immediate feedback. It incorporates both grids and a 'rings of uncertainty' element. This enables us to respond without feeling that we should be making definitive judgements until we have considered not only the case, but also others' responses to it. It is possible to use cases posted on the open web site, or set up 'closed cases' for specific audiences. 'Bryan' (figure 1) is the first Manchester Metropolitan University speech and language therapy case to be presented in this format.

2. A student's journey – Jane Handley

As a speech and language therapy student I frequently find myself faced with difficult decisions that require not only sound clinical judgement but also clear ethical reasoning. Such decisions are often difficult to resolve because they present ethical dilemmas which cannot be reasoned out with logic alone. To achieve the best possible outcome, it seems that a moral judgement is also required. In these situations, finding a way through to the best outcome has, at times, proved extremely challenging.



Figure 1 Bryan (hypothetical client)

You have been asked to provide a second opinion for the parents of a five year old boy, Bryan, who has profound physical and cognitive disabilities.

He lives at home and attends a special educational placement. He has respite care one week in four at a local special unit.

At home Bryan is fed by mouth. His swallow is impaired and great care is needed over the quantity and texture of food given. There is also some oesophageal dysphagia (reflux).

Bryan's parents are unhappy with feeding in school, where they believe he is receiving inadequate nutrition as a result of the amount of time allocated. They are also highly critical of the respite provision.

The respite unit will only accept Bryan on condition that feeding is supplemented by nasogastric tube. The parents feel they were pressured into signing an agreement for this, otherwise respite care would have been denied.

The series of workshops on ethical reasoning in our final year has provided a useful framework for working through ethical dilemmas in practice. By sharing this process in relation to Bryan's case (figure 1, p.E5), I hope to make other students and therapists aware of tools that can help us approach ethical reasoning more confidently.

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Bryan's parents believe he can and should continue to be fed orally without supplemented feeding, and that the necessary resources should be provided to enable him to do this safely and to thrive. Based on the information provided, I hypothesised that their motivation in seeking a second opinion is to gather evidence and support to help them fight for this.

Using the Seedhouse Ethical Grid (Seedhouse, 2007) (figure 2) as a basis for my ethical decision-making, the first consideration in this case is my own competency as a clinician. Am I sufficiently skilled to take on the case? According to the Royal College of Speech & Language Therapists' code of ethics (RCSLT, 2006), members must "act within the limits of personal knowledge, skills and experience" (p.10). At graduate level, a clinician only has basic skills in dysphagia management (RCSLT, 2006). Therefore if I do not have sufficient skills, knowledge or experience it is my

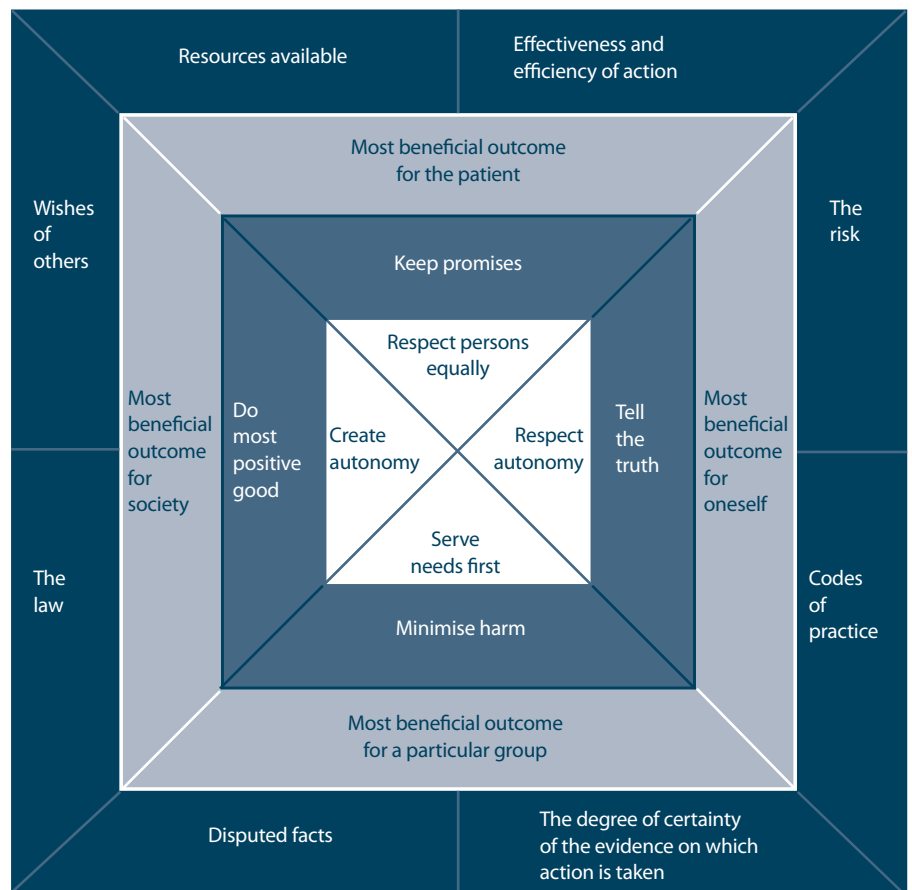


Figure 2 Seedhouse Ethical Grid (Seedhouse, 2007, reproduced by kind permission)

duty to decline this case. However, if I have worked in the field and have appropriate expertise, I can go on to consider other ethical issues before making a decision.

It is possible that the parents want me to comment on issues that fall outside the remit of speech and language therapy. It is important to make explicit to them from the outset the boundaries of my professional competence. They may, for example, wish to discuss the issue of non-oral feeding, but I would need to make clear to them that in this respect I can only comment on the safety and efficiency of Bryan's oral intake (RCSLT, 2005) (*Tell the truth*).

Needs before wants

Another important consideration is the conflict between the principles of *servicing needs first* and *respecting autonomy*. We are required to act in the best interests of our clients and therefore ethically we should serve the needs of the client before the wants (Stansfield & Hobden, 1999). It is important to clarify here that the

client is Bryan and not his parents, which brings us to the issue of informed consent. In the UK, "consent for assessment and intervention of children under the age of 16 will normally be sought from the parent / guardian" (RCSLT, 2006, p.19). Although children under the age of 16 can give this consent in certain circumstances, given Bryan's age and profound cognitive impairment, his parents are responsible for consenting to any decisions made by the healthcare team. According to Richards (2003), "Legally adequate informed consent requires that decisions are informed, competent and voluntary" (p.378). Bryan's parents say they felt pressured into signing the agreement for nasogastric tube feeding, and therefore the validity of their informed consent may be questionable (*Wishes of others; Respecting autonomy*).

From the parents' perspective, they may have felt excluded from the decision-making process and may therefore want me to act as an advocate to give voice to their

opinions. It is important to be sensitive to this, and yet not engage in any negative rhetoric regarding the competency of other professionals. It does not appear that incompetence is suspected - or alleged - in this case, although, if it were, we would have a duty to report it to the Royal College of Speech & Language Therapists and Health Professions Council (RCSLT, 2006).

It seems plausible that an open and sensitive dialogue between the multidisciplinary team and the parents did not occur. The parents' wishes may not have been explicitly acknowledged, and an open discussion of these in the context of wider ethical, clinical and legal frameworks may not have taken place (*Tell the truth*). The issue of non-oral feeding may also have been inappropriately raised. In the experience of Rosenbloom & Sullivan (1996), an ill-considered introduction of a sensitive issue has the potential to cause significant confusion and distress to parents. If this is the case, then it will need to be addressed with the multidisciplinary team to ensure a more positive dialogue between them and the parents is established.

Another important consideration is that his school and respite care may not have enough resources to devote to feeding Bryan in line with his parents' wishes. Indeed, there may be many other children in their care who have an equal right to be fed and cared for (*Resources available; Respect persons equally; Most beneficial outcome for a particular group*).

It is also necessary to consider Bryan's care in the context of *doing most positive good*. According to the Royal College of Speech & Language Therapists, part of the value of dysphagia management is the "safe maximisation of the child's eating and drinking potential, using appropriate strategies that promote safe and adequate nutritional intake within a setting which supports and enhances the child/young person's wellbeing" (2006, p.324).

In addition to the safety and efficiency of Bryan's swallow (which includes the competency of those who are feeding him) we must also consider Bryan's experience

of eating and how this impacts on his learning and socialisation. For example, the experience of being fed may be a tiring experience for Bryan. This may mean that, if it is extended significantly, he may not be able to participate fully in subsequent activities. In addition, Bryan's needs may be such that he requires significant one-to-one attention away from any distractions, meaning he is unable to enjoy the social experience of mealtimes.

Such considerations may not be a priority for Bryan's parents but it is nonetheless important that these are discussed so that they are able to come to an informed decision. It may be that even then parental views remain in conflict with the professional consensus. In this case, clinical decisions should be based on serving the needs of Bryan first, not the wishes of his parents.

In addition to doing most positive good, this case also needs to be considered from the principle *minimising harm*. Bryan's parents are claiming that he is malnourished as a result of insufficient feeding time devoted to Bryan in school (*The risk*). We don't know whether this is fact (*The degree of certainty of evidence on which action is taken*). However, it is privileged information that we are obliged to follow up with the clinician involved in his care, even if the parents have requested a confidential second opinion from an independent practitioner. Furthermore, the parents should be made aware from the outset that recommended good practice is to inform the NHS departments that a second opinion has been sought (RCSLT, 2006).

Through interpretation of the ethical dilemmas in the context of the Seedhouse Ethical Grid, a just solution can be reached that provides the best possible outcome for Bryan whilst respecting his parents' autonomy. Seedhouse recommends that one box, the most salient from each level, is chosen by the clinician, as ethical reasoning leads directly back to clinical decision making.

Principled ethical decision making can lead different clinicians to choose different priorities. In my opinion, the

priorities in Bryan's case are: *Serve needs first; Do most positive good; Most beneficial outcome for a particular group; Resources available*. SLTP

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REFLECTIONS

- DO I GIVE SUFFICIENT ATTENTION TO THE ETHICAL DIMENSIONS OF MY WORK?
- DO I PROMOTE OPEN AND SENSITIVE DIALOGUE WITH CLIENTS AND THEIR FAMILIES?
- DO I HAVE THE SKILLS TO JUSTIFY CLINICAL DECISIONS IF NECESSARY, GIVEN THAT THEY WILL DIFFER DEPENDING ON PERSONALITIES AND CIRCUMSTANCES?

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