Swimming guidelines for adults with epilepsy

Jennifer Burt and Christine Cole describe how guidelines designed to ensure the safety of swimmers with epilepsy were researched, consulted on and distributed.

It is important that people with learning disabilities have opportunities to participate in a wide range of community activities. To support this inclusion agenda greater emphasis is now being placed on the health promotion, facilitation and educational roles of learning disability health professionals (Department of Health (DH) 2002, 2007a, 2007b, Hart 2007). Various studies and government reports have highlighted that people with learning disabilities have an increased risk of health conditions such as epilepsy and other physical illnesses when compared with the rest of the population (DH 1999, 2002). This article describes collaborative work that promotes choice and the opportunity for people with learning disabilities to be included in swimming activities.

Aims and objectives
The objective of the project described here was to produce guidelines that would enable people with epilepsy to participate in swimming safely. The aim was to collate the evidence and produce draft swimming guidelines, and to ensure that the guidelines were then circulated to a range of people as part of a consultation process.

Rationale
It has been demonstrated that restrictions concerning independence can be the most socially disabling factors affecting people with epilepsy (Trimble and Dodson 1994). Therefore it is recommended that health professionals should provide advice to people on lifestyle adaptations that may reduce seizures and help towards maintaining good health. However, this advice should be delivered without unduly limiting activities that bring enjoyment and fulfilment (National Institute for Health and Clinical Excellence 2004, Brodie et al 2005). There are often concerns about keeping people with epilepsy safe in the water, especially in the event...
of a seizure (Kemp and Sibert 1993, Chadwick 1997, Besag 2001), and fear of having a seizure can limit a person's opportunity to be involved in leisure activities (Manford 2003).

Regular exercise that addresses safety risks should a person have a seizure is important for maintenance of general health and bone health (Brodie et al 2005). Swimming is one of the best ways of exercising the whole body with minimum risk of injury. It combines the pleasure of sport with the benefit of fitness (Shaw and D’Angour 1998).

Plante and Rodin (1990) noted that empirical research conducted since 1980 suggests that exercise improves mood and interest, and reduces anxiety and depression. Their review suggests that swimming is beneficial, offering a feel-good factor, and enhancing wellbeing, self-esteem and self-concept. For people with epilepsy, swimming can be a productive therapeutic sport. It is known that this group is more susceptible to developing psychological problems due to the nature of their condition compared with the rest of the population, so swimming could assist with maintaining or improving their health (O’Donoghue et al 1999).

Valuing People Now stresses that people with learning disabilities want to lead ordinary lives and enjoy leisure activities (DH 2007c). Therefore advice about amenities and safety can help individuals with epilepsy to feel included and safe when swimming (Taylor 1996).

Background
The sports inclusion development worker at Barnet Mencap approached a local epilepsy nurse specialist and physiotherapist for support in enabling individuals with learning disabilities who have epilepsy to participate in swimming sessions. The sports inclusion worker was responsible for organising a number of sporting activities for people with learning disabilities, and sought to ensure that the relevant health and safety guidance would be followed. Locally, there had been some hesitation and concern expressed by health professionals and carers about individuals with epilepsy being involved in swimming.

Appleton and Gibbs (2004) note: ‘Adults and children with epilepsy should be encouraged to participate in and enjoy a full social life. Epileptic seizures are less likely to occur when an individual is engaged in satisfying mental or physical activity.’ Even so, in the past, many people were denied the opportunity to swim because of their epilepsy. Sander and Hart (1999) suggest carers and society could be overprotective towards this population. People with epilepsy often encounter discrimination due to ignorance of their condition, and it is important for them to be able to achieve their full potential, face challenges and participate in meaningful social activities (Wilner 1996, Appleton et al 1997, Sander and Hart 1999). In the past, some adults have been denied opportunities to swim in a community setting.

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Initially the swimming protocol involved the gathering of information and research with the aim of developing swimming guidelines for adults with epilepsy and learning disability. But it transpired during the project that most swimming issues and related problems were applicable to any person who has epilepsy regardless of whether they have a learning disability. Therefore the guidelines were tailored to address the needs of all adults who have epilepsy.
The first stage involved completing a literature review to explore what information was available on the subject of swimming. The Psychinfo, British Nursing Index, DH-Data, Embase and Medline databases from 1996 to 2006 were searched for evidence-based research on epilepsy and swimming.

The literature review did not locate any formal research published on this subject, although some anecdotal data of importance was identified. The core group drawing up the guidelines appraised and used elements of literature produced by various epilepsy organisations and other sources such as the National Society for Epilepsy, Epilepsy Action, the internet, telephone enquiries and leaflets. Additionally, guidance on lifeguarding standards from the Amateur Swimming Association and the Swimming Teachers’ Association was reviewed. The core group members examined all this literature and incorporated essential components into the first draft of the epilepsy swimming guidelines.

**Method**

There appeared to be a lack of information and support available for people with epilepsy to take part in swimming. A project group was set up to resolve this comprising doctors, nurses, physiotherapists and representatives from sport and leisure centres, and learning disability resource centres were asked to share their views. The core group members completed the initial draft of the guidelines but it was then decided that the views of other key individuals such as swimming pool staff and social care staff were required to ensure that the draft guidelines reflected their opinions. Therefore a consultation exercise was agreed and organised into two phases.

**Phase one**

A questionnaire was compiled and together with the draft guidelines was circulated to relevant individuals in the local area. The questionnaire sent out in phase one is shown in Box 1.

**Results: phase one**

In the first phase of the consultation 17 questionnaires were sent out to a variety of people (Box 2); 12 were returned, giving a 71 per cent response rate.

**Question 1**

Eleven respondents found the swimming protocol useful and one gave no answer. This suggested support for the relevance of creating the guidelines.

**Question 2**

Nine respondents were satisfied with the information provided in the protocol. One was not and two did not answer the question. This suggested that most of the information contained in the protocol was appropriate. The respondent who was not satisfied with the swimming guidelines stated that they required further information on managing people with profound learning disability, especially those with additional complex needs. This is a valid point although it must be acknowledged that the swimming guidelines are generalised, and it is the role of those who know the person best to adapt the guidelines to ensure they meet specific individual needs.

**Question 3**

The majority of respondents (11) indicated that the swimming protocol would be a useful reference or resource for people with epilepsy, service users and customers. Again, there was one respondent who did not answer this question.

**Question 4**

Six respondents said that no further information should be included in the swimming protocol, but six requested additional information, and some made several comments. Some of these related to grammatical changes; others related to the safety and location of emergency anti-epileptic medication during the swimming activity. This is an individual decision that needs to be agreed following the risk assessment that should be carried out prior to the planned swimming session. This approach is endorsed by the
Amateur Swimming Association (2007) and is included in the swimming guidelines.

One respondent commented on the staffing ratio when supporting individuals in the swimming pool. This was explored further and it posed a dilemma as there appeared to be no evidence or standards that offered guidance on staffing requirements when supervising swimmers who have epilepsy. It is common practice when a person with epilepsy is swimming that a responsible adult accompanies them and this is reinforced by most of the epilepsy organisations. Another respondent requested a protocol for dealing with seizures but this depends on the complexity and frequency of the seizures and a risk assessment is necessary. While in the water, lifeguards are responsible for swimmers and they would manage the situation (Greenwich Leisure Ltd 2005).

Phase two
The comments from phase one were incorporated into the second draft of the swimming guideline. A second questionnaire (Box 3) was sent out with the redrafted guidelines to those who had responded to the original questionnaire and to three other professionals who had expressed an interest in the project.

Results: phase two
Fifteen questionnaires were sent out to a range of people in the second phase of the consultation (Box 4), and eight were returned completed – a 53 per cent response rate.

Question 1
Six respondents were satisfied with the revised guidelines and two were not. However, their dissatisfaction related to grammar and the style of the guidelines and not the content. The changes to the grammar of the text were made but the introduction to the swimming guidelines was retained in the document. The core group decided that the introduction was a necessary component as it provided the rationale for having swimming guidelines.

Question 2
Six respondents did not require any further information added to or deducted from the guidelines. Two respondents indicated that they would like additional information and offered some valuable points. These were in reference to modifying the layout of the guidelines to improve the clarity of the section concerning the recognition of seizures and triggers, the swimmer’s companion being within reaching distance of the person while he or she is swimming and ensuring that the companion is a competent swimmer. These points were included in the revised guidelines.

The second respondent requested guidelines for lifeguards and supervisors. This was not within the scope of the guidelines as the lifeguards have their own professional regulations and employment conditions. However, the guidelines do highlight the importance of informing the pool attendant if a person has epilepsy (Walker and Shorvon 2003).

Amendments were made as a result of the responses from the second consultation and the final version of the swimming epilepsy guidelines was produced.

Discussion
The first and second phases of the consultation enabled the core group to collate data and produce swimming guidelines that incorporated the views of a range of health and social care staff. Overall, most respondents gave a favourable reaction to the guidelines. Positive comments made by respondents included: ‘Really pleased that you have formalised this great piece of work’; and ‘Very comprehensive and sensible’. These illustrate the importance of the swimming guidelines as a valuable and practical resource.

Questionnaires often produce a poor response rate (Smeeth and Fletcher 2002) but in this project the response rate in both phases was above the average expected range.
practice & research

The pool lifeguard must be made aware of any swimmer who has epilepsy

One of the problems encountered during this project lay in defining a ‘competent swimmer’. Eventually the group found a creditable alternative – ‘good swimmer’ – which is understood in the sport of swimming (Swimming Teachers’ Association 2006). This definition was incorporated in the guidelines.

Another concern was difficulty in obtaining a formal quotation for the ‘whistle procedure’ used by pool lifeguards. This is an alert system and emergency measure for lifeguards. Subsequently a citation was sourced from Greenwich Leisure (2005) and was included in the swimming guidelines, and currently the International Lifeguard Training Program (2006) is acknowledged.

The guidelines that were finally produced support the rights of people with epilepsy to participate in swimming activities and have been endorsed by the local primary care trust.

Conclusion

The swimming guidelines are designed to support learning disability organisations, mainstream leisure facilities and primary health care services. Limited research was found on the subject of swimming and epilepsy, and it is hoped that this project will stimulate further study. The guidelines are relevant to all individuals with epilepsy and it is intended that this work will be shared with interested parties such as people with epilepsy, GPs, residential services, carers, leisure centres, epilepsy voluntary organisations, networks, learning disability organisations, the London Sports Forum for Disabled People, the Amateur Swimming Association. Special Olympics and other NHS organisations.

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References


