

Starting higher education: experiences of UK students

Over recent years there have been many remarkable academic achievements by young people with even the most severe forms of EB. However there have been reports of continued difficulties and inadequate support, and some have been forced to discontinue their studies due to lack of facilities to address their specific needs. In 2007, DebRA UK sponsored a study of the experiences of 27 UK students with EB, designed to explore the effects of EB on students in order to discover ways in which DebRA could facilitate and support them to ensure they share the same academic opportunities and enjoyment of student life that their peers do. The survey was undertaken by Mavis Hartley PhD, an experienced EB nurse and Chartered Psychologist.

The full report, which covers many aspects of student life, is available from DebRA UK john.dart@debra.org.uk

The main suggestions made by current students to others with EB considering entering higher education are summarised below.

- **Inform** university staff, their medical teams and support staff about EB its treatment and the constraints and the specific needs of students with the condition.
- **Commence** applications for grants and support early in the preceding academic year, particularly when new arrangements for personal care, specialised equipment, transport or learning support will be required.
- **Investigate** 'on campus' accommodation available for students with EB, e.g. en suite bathroom and space to store dressings
- **Advised** students with impaired mobility to pay greater attention to the provision of disabled access, including parking, to all campus locations(accommodation, lecture rooms, social areas, canteen, etc)
- **Consider** the balance between remaining living at home, where care arrangements are probably already established but which may restrict choice of university or course, against moving to living independently which offers increased choice but where severely affected individuals often faced considerable challenges in daily life.
- **Choose** a course, particularly if vocationally based, which offers career prospects that are within the physical capacities of the student. Be aware of any placement requirements.
- **Organise** the provision of equipment, scribes, and extensions for assignment submissions in advance, if possible.
- **Expect** the unexpected., e.g. short time allowed between lectures in different parts of the campus,

When making an application to universities and colleges their advice was

- Discuss the implications of EB at open days to allow comparisons to be made regarding the support on offer at different Universities.
- Arrange an appointment with disability coordinators, and placement advisers prior to open days or interviews and, if accommodation difficulties are anticipated, request the accommodation officer's presence.
- During open day visits travel the route from the residences to the learning, social, health care and shopping areas to ascertain that regular access to all these facilities are feasible and include a visit to the relevant floor at the library.
- Have the confidence to explore the possibility of going to a university away from home with a pre planned care support system.