

An exploration of information needs for adolescents with epilepsy:

Epilepsy is the most common neurological disease affecting children and adolescents (Wheless & Kim 2002, Appleton & Neville 1999). Approximately 1 in 200 people under the age of 18 years in Ireland have epilepsy (EI, 2015a). It is a complex disease requiring ongoing care and various lifestyle adaptations. Education about treatment, lifestyle changes and seizure management are important particularly for adolescents and families so the disease is managed effectively.

Adolescence is the period in which children develop and begin transition to adulthood. Young people experience many changes and while they wish to become more independent, there is still much to learn in order to achieve the independence they so truly desire. The adolescent period becomes more challenging with the presence of a chronic health diseases (Suris et al, 2004), for example cystic fibrosis, diabetes and epilepsy. Teens do not wish to stand out from their peers but due to a disease such as epilepsy that causes unprovoked and unpredictable seizures, there may be times when a young person will be noticeably different. As adolescents with epilepsy begin their transition to adult services, they need to become more informed about their disease and be aware of the potential risks and triggers for their seizures (England et al, 2012).

Subsequently, information plays a vital role in the ongoing management of the disease. With the increasing presence of health information available on the internet coupled with the high volume of adolescents that have access to the internet on a daily basis, there is the opportunity for adolescents to learn more about their illnesses or diseases. The prevalence of Health Information technology (HIT) will have an expanding role to play for people with chronic illnesses (Healthy people.gov 2016, Himes & Weitzman 2016).

This research study investigated through a literature review what a complete list of topics should contain and from the primary research whether adolescents believe that the information available to them is complete and useful. It also researched the sources they use to seek advice and information, whether they prefer information in digital or paper format.

The findings suggest that health informatics is becoming a major part of epilepsy care in Ireland and there are many projects currently underway and in the pipeline such as the lighthouse project and epilepsy EPR (eHealth Ireland, 2016). It is also evident that availability of complete and useful information is essential for adolescents with epilepsy regardless of format, once it is appropriate for their communication needs and level of health literacy. A complete list of topics was produced from the literature review and more primary research is needed to ensure all topics are approached by HCPs with adolescent that have epilepsy.