RCPCH EQIP

Epilepsy quality improvement programme

Aneurin Bevan University Health Board

Establishing a Transition Service

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Aim:

90% of all 14-16 year old with epilepsy will have been sent ‘Ready, Steady, Go’ forms by May 2020.

Background

Paediatric patients with Epilepsy reaching transition stage, were only offered one joint “handover clinic”. The patients and their families had little or no preparation for transition. Likewise, there was little preparation by clinicians or a set proforma of topics to discussed.

An urgent need for improving the transition of our patients to adult neurology services, was identified by both teams.

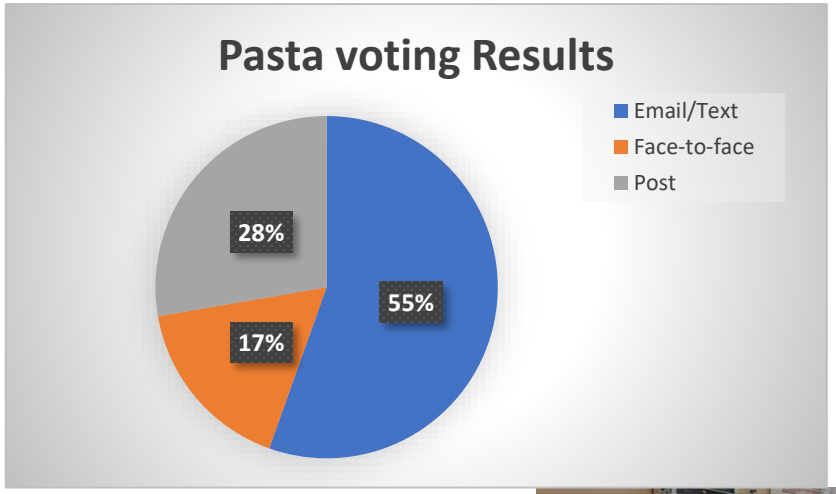
We decided to adopt the ‘Ready Steady Go’ Transition Programme. This provide 3 opportunities to discuss transition with young people who have a long term health conditions. This was developed by the Southampton Children’s Hospital.

This is a successful tried and tested tool that helps prepare the young person for the move from children’s to adult services. Helping them gain knowledge and skills to manage their own health.

Tests and change:

Cycle 1: Establish how patients and families would like to receive information about their healthcare i.e. surveys and appointments, using pasta voting.

- Pasta Voting completed (Dec 2019) 3 Shoe boxes left in outpatients departments (2 different locations). Parents/ children asked to vote by posting one piece of pasta into the shoe boxes labeled clearly with options illustrated on the pie chart. Email/text, Face 2 face, or Post.
- Engagement from families was good. Easy to set up. This indicated a preference of patients and their families to receive information via email or text (55%). This showed a patient centred approach to care.
- As a result of this outcome the CENS have adapted their documentation to record the patients e-mail address, for those who wish to use this method.
- Although the exercise demonstrated what we thought might happen, that there remains a significant numbers of people who want paperwork sent by post or wish to complete it in person at the clinic. We need to be prepared to offer all 3. Needing pens and printed forms readily available in clinic settings.



Tests and change:

- **Cycle 2:** Test the efficacy of completing questionnaires. This was done with patients/families face 2 face at clinic, via a telephone consult, post and email. We realised that we needed to create word documents of Ready, Steady, Go leaflets so that they can be easily edited on email/text for digital method to be successful. Furthermore that we would need some form of feedback from our patients and families to understand if the changes proposed to service were negative or positive.
- **Cycle 3:** Set up shared secure network folders for storing/sharing questionnaires, feedback, patient lists & EQIP progress. Creating waiting lists for joint clinics/ clinic templates.
- Develop care pathways for main stream and complex needs patients, to ensure that every patients journey could be replicated. Agreed main stream patients would complete documentation Ready, (11-12yrs) Steady, (13-14yrs) Go (15-16yrs).
- Complex needs patients start this process later, as remain within paediatric remit until 19yrs of age. Starting Ready (14yrs), Steady (16yrs) and Go (18yrs).
- It is important to understand that R/S/G documentation is aimed at main stream children. Even though there are easy read versions of the forms they are still not suitable for those patients with very complex needs and no verbal form of communication. CENS developed of a form that was more sensitive to those patients to ensure they were not disenfranchised.
- **Cycle 4:** Transition Watch List. In preparation for the IT challenges of this project we have now have robust ways of tracking patients, complete with reminders for each stage of transition. Because this is on the digital hospital patient record, we would easily be able to roll this method out to all chronic disease transition teams across the health board with minimal extra work if it is successful. This system is more robust than relying on excel database. All R/S/G forms are uploaded, once completed to digital hospital patient record. So accessible to all professionals.
- **Cycle 5** – May 2020 – Additional task of piloting a video consultation using the 'Attend Anywhere' software platform. At joint transition clinic with 2 consultants, 1 specialist nurse and patient and carers all in separate locations.

Please could you provide feedback on your visit today…

1. How easy were the forms to complete? On a scale of 1-5 (1 being very easy, 5 being very difficult)

1 2 3 4 5

2. How useful were the forms/consultation regarding transition? On a scale of 1-5 (1 being very helpful, 5 being very unhelpful)

1 2 3 4 5

After each nurse led appointment each family were asked for feedback:

How easy was it to complete the forms on a scale of 1-5.
1 being very easy – 5 being very difficult.

How helpful was it to complete the forms with the nurse?
1 being very helpful – 5 unhelpful.

Feedback:

- The majority of responses have been very positive with most families scoring 1, for both questions.
- Some families added the comment that only with a nurse going through the form with them, would they have scored so positively.
- Otherwise they would have found the form quite difficult to complete/understand.
- We did have less favourable feedback from some families where there were significant co-morbidity, such as learning difficulties, ASD. Especially where epilepsy was not the lead health condition.
- Most families have commented that they have a better understanding of transition process and what to expect in adult services.
- “The questionnaires are lengthy”.

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Transition Programme for Children with Complex Needs

We want to support you and your family as you grow up and transition into adult care.

Name: Date of Birth:

Hospital Number: Named Nurse:

Review one: Ready Review Two: Steady Review 3: Go (please circle)

Knowledge and skills	Yes	No	I would like extra advice or help	Comments of Young Person/ Parent/Carer	Comments from CENS
Does the child/family have a good understanding of the child's condition?					
Do they know medications, names, doses, how often, reordering medication?					
Do they know who is who in the medical team?					
Do they understand the differences between paediatric and adult healthcare?					

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Challenges

- Still need to link the delivery of ‘Ready, Steady, Go’ questionnaires for patients, via Doctor/ Doctor. This is a platform used by our health board to automatically (or manually) push information to patients before appointments, by email or text, and allows them to enter Patient Reported Outcomes/Questions in their own time before clinic. This information is stored on that system & viewed electronically on a dashboard by the clinicians whilst sat in clinic (or before if needed).
- For some patients contact details frequently change and are not always updated accordingly. These need checking regularly and should include email addresses for this process to work. (Access to Myrddin/WPAS)
- Getting Clinic Codes for Nurse Led Transition Clinics to run. Booking patients appointments and detailing outcomes from clinic lists. Due to cost.
- COVID 2019. We needed to find different ways to support patients. Face to face clinics were predominantly replaced with telephone consults. ‘Attend Anywhere’ video consultation software is also available for those with internet access at home. Whilst this works well for one to one patient consultations it was not so positive at a joint transition clinic.
- There were technical difficulties with 4 different devices signing in, impacting on sound quality. The overall opinion was that it difficult to appreciate who was needing to speak next, which interrupted the flow of conversation. It was tricky to interpret any non verbal communication and develop a rapport with new professionals. It was decided that we would therefore try to resume face to face clinics in suitably social distanced areas, for all further joint transition clinics.

Outcome Data

- 98% of all 14-16-year olds with epilepsy were sent the ‘Ready, Steady, Go’ questionnaires by May 2020.
- The Watch list, is working well. Easily accessible to both Paeds/Adult services. Provides timely reminders to epilepsy team when a patient reaches the next stage. CENS begin by adding patient details to the Watch list once nurse led review is completed. Detailing date, and stage of next review/Follow up. This is then highlighted in Red on CWS if date breeched. Making the stages much easier to monitor and track.
- Since March 2020 weekly Nurse Led Transition Telephone Consults have been set up and are running both in North & South regions of ABUHB.
- Joint transition clinics are running in areas where we can maintain social distancing. First clinic was cancelled in April 2020(COVID 19).
- Two clinics run side by side. In the same OPD. Nurse led clinic’s led by AENS, with CENS in attendance. Consultant led clinic’s led by Adult Neurologist with Paediatrician with Specialist Interest in Epilepsy in attendance.
- These clinics are held on a Friday afternoon in an adult out patient area every 2 months. (June, August, October, December 2020)
- Each clinic has its own waiting list. Managed by CENS.
- So far, 17 CENS nurse-led clinics and 2 joint Transition Clinics have taken place.

Next steps

1. Embedding the routine collection of transition information into regular clinical practice.

2. Continue the face to face joint transition clinics.

3. Engage with Values Team at ABUHB to support delivery of questionnaires to patients via Doctor/Doctor.

4. Ensure there are paper versions of R/S/G forms readily available in clinic. Hard copies will be posted for those with a preference for post.

5. The project has proven that the ENS are essential part of the Epilepsy Team. Therefore we need to retain resources and improve numbers. Possible new business case for transition nurse.

6. Now realising multiple aspects of care involved to develop a robust transition service, e.g. needing to include transition social workers, who can help with capacity & consent, learning disability nurses, continuing care teams, specialist teams and voluntary organisations. This is vital for the YP with learning disabilities & complex needs.