PS2/1

Review of motor neuron disease (MND) referrals: expected outcome v actual outcome

Summary

An audit of referrals made over a five year period of clients with MND referred for wheelchairs.
Was what was requested issued?
What was the impact on the service?
Was it appropriate for clients' current and future needs?

Aims & Objectives

1. To evaluate initial referral care pathway against the actual care pathway delivered for clients with MND.
2. To ensure that a "right first time" approach is delivered irrespective of the information received.

Background

Clients referred to the wheelchair service (WCS) with a diagnosis of MND have a rapidly deteriorating condition which is prioritised by the service. Initial referrals are received from clinical nurse specialists, consultants, GPs and therapists. The WCS has noted that in some instances the care pathway suggested by the referral differs from the care pathway provided by the WCS. This could have resulted in unnecessary clinical intervention and distress prior to provision of the appropriate care pathway.

There are currently no NICE guidelines for people with MND. The National Wheelchair Managers Forum has agreed that clients with MND should be prioritised. In most cases MND is a rapidly deteriorating condition, and provision of mobility and supportive seating equipment can be difficult to provide in a timely manner. Many patients diagnosed with MND are still in the grieving stages of the condition when referred to the WCS for the first time. Many will not want to consider that in a very short time they may require a wheelchair with more support, or powered mobility.

This audit is to evaluate need and provision whilst considering forward thinking to provide appropriate mobility and seating equipment first time.

Paper and electronic records of the 33 clients referred to the WCS in the five year period were analysed for number of referrals and what the referral was for (powered or manual wheelchair, cushions or seating). This was looked at for trends as to whether they were seen by a member of the WCS team and whether they were issued the equipment requested in the referral, for both initial and subsequent referrals. Results showed there was a longer period of time between referrals for those who had a visit from a clinician originally, and also that only 78% were issued the equipment requested on the original referral compared with 100% of those who did not have a visit.

Discussion

By visiting all clients referred with a diagnosis of MND there is a chance to improve quality and build a relationship with families over what is likely to be a very short period of time (average 9 months from referral to death). Assessment for appropriate equipment can increase the length of time between referrals (from 4.27 to 9.00 months) and ensure the WCS is not a "faceless" service, which makes approaching the service in times of change much easier.

References

1. NICE, (2010) Motor neurone disease: The use of non-invasive ventilation in the management of motor neurone disease. NICE Guidelines July 2010
2. MNDA, (2014) Statistics of MND – Information Sheet H. Revised July 2014

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Weekly drop-in clinic:
a six-month pilot at Camden & Islington wheelchair service

Summary

Camden & Islington wheelchair service (WCS) decided to carry out a 6-month pilot of a weekly drop-in clinic to help provide clients with a different way to access the WCS. The pilot has been successful and there are plans to continue providing and developing the service.

Aims & Objectives

The aim was to provide a different type of approach to the standard pre-booked clinics and to offer clients an alternative way to access the WCS. It was also to see whether or not this positively impacted the waiting list.

Background

Historically, the WCS offered pre-booked clinic appointments to clients, compared to some other healthcare services which are able to be more dynamic with the provision of clinics, such as NHS walk-in centres, sexual health clinics and dentistry. Sometimes when screening referrals, if the therapists in our service felt that an intervention could be provided promptly, then the issue with the equipment could be resolved, and the issue going from being an 'acute' problem to a ‘chronic’ one could be avoided. These types of interventions were perceived to be less time consuming when provided in a timely manner. It was felt that if a drop-in service could be provided for clients, then some issues could be resolved on the day. Other issues may be resolved by first seeing a client at a drop-in clinic and then the client being sent the equipment or parts directly by post or via the approved repairer.

In addition, the drop-in service should help clients with urgent requests or needs by being able to access the service quickly without having to pre-book.

The pilot was formed by holding a meeting with the service staff to identify the pros and cons. The team thought about any problems which might occur and, where possible, how to avoid these from happening. Jobs were given to different team members; these included drafting a screening form, feedback form, inclusion criteria and information leaflet to distribute for promotion; looking at stock levels for basic parts, such as footplates, backrests, backposts; and other basic accessories and writing up processes so that everyone would know what to do, what to expect and how to run the clinic on the day.

It was important to ensure that people who were on the waiting list the longest were told about the new service first. Once the first week had gone by, a therapist went through the waiting list again to remind clients about the new service. That week, the duty therapist started to let clients know about the drop-in clinic and the administrative team started to inform clients and referrers about the new clinic. All referring community services were notified of the new clinic, via their service leads, from the third week.

The pilot ended on the 11th March 2015, and at the time this piece was submitted, we had on average seen just under the number of clients we would have scheduled in for a normal clinic day. We have had 98% positive feedback from clients and our commissioners were very happy with the new service. We are moving forward with the project by reviewing the clinic to establish how we may improve upon it to keep on providing a drop-in service in the future.

Discussion

Our team's main concern was that we would have more clients attend than we could have coped with. To date, we have not turned anyone away; however, a handful of clients who arrived chose not to stay and there have been a handful of inappropriate attendees to the drop-in clinic.

Previously when clinics were pre-booked, the service was able to see up to 6 clients per day. To date, we average 5 per day and the maximum being 10. We measure our success based on seeing 5 clients or more per day, as well as the number of clients removed from the waiting list and the number of discharges due to the resolution of our clients' issues. In addition, we have no DNAs, as appointments are not pre-booked and this relieves our administrative team of booking appointments.

Examples of the types of services which we have provided at the drop-in clinic are: clients being weighed using wheelchair-accessible scales, pressure-mapping, training on the use of equipment, re-measuring, growing children's equipment and general reviews.

Drawbacks of this type of clinic are that it is not suitable for all clients, e.g. clients with more complex input required, clients unable to wait in the waiting area, and clients unable to get themselves to the clinic.

An audit is currently underway to analyse the data and feedback gained from the drop-in clinic which will be presented at the parallel session. We have plans to increase attendance each Wednesday and to look at making the service more accessible in other ways. Further discussions are underway as a team, to see how the model should evolve.

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PS2/3

Pilot research study into the effects of sleep systems on quality of sleep, pain and joint range

Summary

In 2013 Hounslow wheelchair service (WCS) won a *Dragons' Den* style competition within Hounslow Community Healthcare (HRCH) Trust. The bid was for funding for a pilot study researching sleep systems as part of a twenty four hour postural management programme. Consideration of twenty four hour postural management and provision of sleep systems was patchy within the trust. The pilot study consisted of four participants over a period of six months. Evidence for joint range, quality of sleep, quality of life, pain, and goal attainment scaling (GAS) outcomes, were gathered at baseline, with data then being collected at monthly intervals. The outcomes have been positive, with sleep quality having improved, quality of life for both parents and participants having improved, and GAS outcomes having been met and exceeded.

Aims & Objectives

We found that there is little research evidence for clinicians to support provision and funding of sleep systems. Our aim was to obtain evidence of the clinical and quality of life effects of sleep systems for service users and carers. Also to ascertain any associated cost savings that had been made in our participants' overall care. Our objective was to expand the remit of Hounslow WCS and establish a Twenty Four Hour Postural Management Service. The information gathered from the pilot study would inform us how to deliver the service, budget requirements, and assist with building a business case to present to commissioners.

Background

The aim was to build on the evidence that has already been collected through previous research by building on their methods. A Mac Keith Multidisciplinary Meeting formulated a consensus statement concerning postural management for children with cerebral palsy. 'Children in GMFCS groups 4-5 should start twenty four postural management programmes in lying as soon as appropriate after birth, in sitting from 6 months and in standing from 12 months.' Both Terry Pountney and Ginny Humphreys have conducted research which also supports the use of sleep systems.

Materials and Methods: In January 2014 we began a pilot study to measure the effect of the sleep systems. The four participants were aged between 3 and 21. We used the Chailey sleep questionnaire for the assessments and for the ongoing reviews to record changes in sleep quality, posture and use of the system. Sleep quality was also recorded using the Chailey sleep diaries. To assess quality of life for the family and the participant we used GAS. Pain levels were measured using the paediatric pain profile; postural assessment using the Oxford Centre for Enablement forms, and the neutral zero method was used to record joint range.

Having reviewed the sleep systems available we chose the Symmetrisleep system. This had a wide variety of options, could be used on any bed and could be transported with ease as many of our service users travelled abroad. The ideal was to use one system to limit variability in the results but, where this could not meet the participants' needs, alternatives would be considered.

Results: The study is still ongoing although preliminary results are positive. One participant was waking every 40 minutes to 2 hours and he is now only waking once during the night. The sleep system is now managing his posture at night and his tone has reduced. Another participant was waking regularly throughout the night as she would extend and scissor her legs which would cause discomfort. Her posture is now maintained and she is sleeping through the night. Her parents have also noted that her arms, which used to be held in flexion, are more relaxed and extended. Both parents have reported that they are feeling more refreshed as they have uninterrupted sleep. In one case the whole family sleep in one room and so this has improved all their sleep. All have reported that their GAS outcome measures have been met or exceeded. All participants' joint ranges have been maintained, and their pain has not increased, even, in some cases, decreased.

Discussion

The Chailey sleep questionnaire and sleep diaries have been invaluable in recording the level of detail required for prescription.

The borough has a very diverse population. Clear pictorial user guidelines have been critical, as some of the participants have English as their second language. The clear guidelines have meant the systems have been used correctly and consistently.

Another crucial aspect is that we have given the families close support. Two weeks after provision, a visit is made to assist the families and then once a month. In some cases we have been there for emotional support, some families have been, and still are, struggling and we are there to help ease some of their carer burden. By visiting regularly this has also enabled us to react quickly where improvements need to be made, and we have been able to see how rapidly changes in sleep quality have occurred. In rolling out the project we will need to ensure that we have the staffing to enable us to give our families support to ensure the success of the systems.

The study has helped us to establish service delivery and budget requirements. Our trust is supporting us in funding this for another year. We are writing a business case which is being presented to our commissioners to become a Twenty Four Hour Postural Management Service. In recognition of our work our trust nominated us for a Health Service Journal award in the Compassion in Care category; we were then shortlisted as finalists.

References

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