APPG on Stem Cell Transplantation meeting, Monday 24th February 2014, 3-5pm

Attendees

David Burrowes MP
Mark Tami MP
Baroness Masham of Ilton

Guy Parkes, NHS Blood and Transplant
Vicky Griffin, NHS Blood and Transplant
Pip Patrick, CR-UK and Cancer Trials Centre
Rebecca Roberts, Cells4Life
Jo Taylor, Cells4Life
Roger Dainty, Future Health
Paul Colville-Nash, Medical Research Council
Bob Dalgleish, Fanconi Hope
Lionel Salama, Hype
Christopher Francis, Hype
Andrew Parker, Department of Health
Stephen Dobra, Department of Health
Chandni Kerai, Bioindustry Association
Melissa Fehr, Patient Speaker
Jet Black, Patient Speaker
Henny Braund, Anthony Nolan
Richard Davidson, Anthony Nolan
Anneliese Levy, Anthony Nolan
Katie Begg, Anthony Nolan
Victoria Moffett, Anthony Nolan
Rebecca Gladstone, Anthony Nolan

Clarification on issues surrounding ethnicity data coding and data collection

The APPG had sought clarification on a letter sent by Anthony Nolan and NHSBT outlining views on the discussion around ethnicity coding at an APPG meeting in September. Victoria Moffett and Guy Parkes outlined that the original discussion had identified lack of uniformity in ethnicity coding as a cause of the sector being unable to accurately identify the unmet transplant need. The two organisations agreed, but were concerned that the APPG may have understood that this was the only in cause. They added that the lack of resource in the sector for data collection and statistical analysis compounds the problem.

Main discussion: Survivorship: the provision of late effects care for bone marrow transplant patients and their families

Melissa Fehr, patient

Melissa Fehr spoke about her experiences of myelodysplastic syndrome (MDS), for which she had an allogeneic stem cell transplantation in July 2009. Prior to her transplant, Melissa had needed four transfusions a week (two with red blood cells, two with platelets) to keep her alive, as MDS patients have no stem cells to enable the production of new blood cells.

She spoke about the physical side effects of her transplant, which she experienced in the months following. She had been discharged three weeks after her transplant, then readmitted two weeks later with headaches caused by her medication. Melissa was then able to spend two days at home before being admitted to hospital for five weeks with meningitis. She was later diagnosed with a fungal infection in her liver, which would normally result in hospital admission, but Melissa managed to negotiate in-patient treatment, as she'd already spent so much time in hospital. As liver infections can be very slow and difficult to deal with, Melissa had to return to King's Hospital every day for four months.

She mentioned the financial difficulties her and her husband faced because of this – they had to purchase a car to drive to the hospital appointments as Melissa could not use public transport and her husband could not work so that he could drive her to hospital. He had to drive Melissa to and from the appointments but could not leave the car in the car park because of restricted access and because they could not afford the charges. As Melissa did not have cancer, she was ineligible for free parking under hospital guidelines, despite undergoing a similar treatment regime. Cancer charities were also unable to help advise her as a result. She explained that despite help from her employer and understanding from the moorings where her house boat was located, she and her husband incurred significant debts, from which they only recovered two years later.

Melissa also spoke about going through early menopause as a consequence of treatment which resulted in serious acne. This prompted interference from strangers which she found humiliating. She described the process of finding a suitable hormone replacement therapy as very personal, with the need for trial and error. She was referred to a gynaecologist who she described as 'unhelpful', resulting in a three year attempt to find the right HRT for her.

Both she and her husband felt failed by the benefits system. Due to living on a house boat, they do not have a mortgage or pay rent – instead they are committed to repaying personal loans and pay mooring fees. Because of this, they were not entitled to benefits. Furthermore, because Melissa worked for a small company, they had little understanding of statutory sick pay and struggled to find out more from the DWP. Instead, her employer offered to cover their outgoings as the employer could not afford to pay her full wage.

She summarised by stating that, although she did not suffer badly from Graft vs. Host Disease (GvHD), the first six months after her transplant were particularly hard to cope with due to early menopause and the effects of immuno-suppressants.

David Burrowes MP asked if she noticed any change in the level/standard of care she received in the pre and post 100 day period.

Melissa explained that when she went to her GP or pharmacist for repeat prescriptions in the post-100 day period, they often had little knowledge of her condition, meaning she often had to explain and justify the prescription dosage. Overall, she preferred to deal directly with the transplant centre as it was much easier.

Jet Black, patient

Jet Black spoke about her experiences of multiple myeloma. She was diagnosed after her kidneys failed and tests led to a bone marrow biopsy. She undertook a clinical trial involving chemotherapy, steroids and an autograft transplant which took her into remission, however she relapsed after five months. She had her allogeneic transplant in May 2012.

Her pre-100 day period was relatively problem free, with no change noticed between the pre-100 and post-100 day period, apart from nausea and fatigue as a result of immunosuppresants. However she has developed chronic GvHD during her late effects period. She developed an intolerance for hot/spicy/pickled/scratchy foods and found that her mouth became very tight. She also developed vaginal GvHD leaving her vagina sore and tight and sclerodermatous GvHD within a year of transplant - this has significantly restricted her mobility. Tests also found that between October 2012

and 2013 she had lost a third of her lung capacity and had developed rheumatism in her joints.

Jet also mentioned the psychological late effects of her transplant. She described a feeling of abandonment she felt as her support system lessened over the months following her transplant and how overwhelmed she felt at the thought of returning to a normal life. Jet had to wait to receive counselling, as there was no-one in this post for a time following her transplant. She was later prescribed anti-depressants by her GP and still takes them after her anxiety returned when she tried to reduce her dose. Her social life has also diminished significantly due to her weakened immune system and lack of energy.

She is currently experiencing mild gut and eye GvHD and continues to struggle with sclerodermatous GvHD and the subsequent reduction in mobility, as well as shingles, however her effects are manageable. She is also currently undergoing extracorporeal photopheresis for her skin. She has experienced good care co-ordination between hospital departments and between the hospital and her GP.

She concluded by stressing that multiple myeloma is not curable and that she expects to relapse again in the future.

David Burrowes MP made his apologies and left for another engagement.

Mark Tami MP introduced himself and took over as Chair.

Mark Tami MP, father of a patient

Marks son Max was diagnosed with acute myeloid leukaemia aged nine. Chemotherapy treatment triggered tumour lysis syndrome, a condition where the white blood cells break down too quickly, which left him in intensive care with only a ten per cent chance of survival. During this time, He had to be resuscitated, leaving him with a high probability of brain damage. While this didn't happen, the condition led to a slow recovery in his kidneys, leading to high blood pressure and the possibility of permanent encephalitis. This meant that Max could oscillate between periods of mental clarity and periods in which he experienced effects similar to those seen in people with Parkinson's disease.

Max was found to have a chromosomal abnormality, meaning the standard treatment regime would not be successful, leaving a bone marrow transplantation as his only option. Mark stated that he did not want to repeat Melissa and Jet in explaining the physical side effects of transplantation, however briefly mentioned that Max suffered from skin and stomach GvHD, which resulted in Max having to be fed through a tube for two months and left his body looking like it belonged to somebody significantly older.

Although Mark and his family did not struggle financially, during the periods Max was in hospital Mark came into contact with many single mothers of blood cancer patients, or those with little or no family support, who had run up significant debts due to the time of prolonged illness. Despite having a well paid job, Mark's family were also financially affected after the long period of time associated with transplant recovery. He reiterated Melissa's point that the benefit system needs reforming in order to support people in this situation.

Mark also mentioned the effects of the cancer and treatment process on the family of the patient – focus is understandably on the patient with little thought given to

supporting the family. This is something Mark's younger son struggled with when Max was undergoing treatment.

Max struggled psychologically with his illness, particularly due to a lack of understanding because of his young age. He spent two years in and out of hospital, which meant he found it very difficult slotting back into school, both socially and in terms of the curriculum. He was only given three hours of personal tutoring a week by the Local Authority once he had returned home and this support dropped off entirely when he returned to school – Mark argued that children need this support most when back at school and in subjects that are noticeable difficult to catch up on. Currently, pupils only receive extra support once identified as having a special learning need, rather than having missed periods of their education. He recognised that his family were able to pay for additional tutoring for Max, but most aren't able.

There is currently no system in place for flexibly integrating children who are recovering from cancer back into the education system and similarly, there is little to no training or support for school staff or peers . Mark identified changes to physical appearance and a misunderstanding that cancer is contagious as two barriers to reintegrating young cancer patients with their peer group.

Mark also encountered issues with obtaining repeat prescriptions for his son, and often had to justify the prescription dosage to doctors/pharmacists with little or no knowledge of Max's condition. He is able to go to the local hospital for most concerns and is sent to the transplant centre for more complex issues.

Katie Begg, Head of Policy and Public Affairs at Anthony Nolan

Katie gave a presentation on Anthony Nolan's latest policy campaign (attached), which looks to standardise the standard of late effects care so that every blood cancer patient has easy access to a full late effects service regardless of where they live in the country.

Key recommendations:

1. NHS England to take commissioning responsibility for the whole pathway with shared care arrangements and subcontracting for key phases of the treatment.
2. A set of national guidelines should be drafted and adopted to make clear what constitutes a late effects service and how it should be delivered. Rehabilitation and psychological support should form part of this. These guidelines should be adopted and endorsed by commissioners and form a mandatory part of the commissioning process.
3. Returning to work and active life should be recognised as a key health outcome for BMT patients where appropriate. As children grow up, support in further education and work should form part of this strategy, recognising that time lost through treatment in earlier stages of life is likely to impede upon progress in later years.
4. Appropriate support services should also extend to family members, recognising the impact cancer and transplant care can have on them as they support family members receiving treatment.
5. A BMT research and clinical trials network should be established to build capacity and strengthen the research community in this area.

Another recommendation is a review of the clinical relevance of the 100 day marker currently used as the cut off point for centralised commissioning in NHS England.

Steps are being made towards this, with industry stakeholders, including the Clinical Reference Group on Bone Marrow Transplantation submitting a change proposal on the issue to a current consultation led by NHS England.

There also needs to be a national audit of current late effects clinics in order to establish exactly what services are being offered at differing clinics across the country. The British Society for Blood and Marrow Transplantation has agreed to carry out this work.

Anthony Nolan is soon to begin piloting three Anthony Nolan Nurses in various transplant centres across the UK. These clinical nurse specialists will focus specifically on the post-transplant period and will be the point of contact for all support services. They will be able to refer care directly or signpost patients to other services, and will act as the point of contact between the tertiary centre and primary or secondary care providers.

Lionel Salama asked Katie whether they have looked at sharing best practice with international late effects care models. He used the USA as an example, where post-transplant patients are designated a specific patient support team.

Katie replied that the campaign uses NHS England as a point of focus and that, although Anthony Nolan does advocate for patients, it does so in a way that is different to the meaning in the US. She agreed that Anthony Nolan should draw on the experiences and knowledge of international institutions which have far better information on the patient post-transplant experience.

Anneliese Levy, Patient Information Manager at Anthony Nolan, asked Melissa, Jet and Mark how much information they received about the possibility of late effects, and if they felt prepared for the post-transplant period.

Mark replied that he and his family felt bombarded with information in the first instance yet, at the same time, the potential variation in late effects means that not everything could have possibly been covered. They expected Max to experience external GvHD (skin), however they were not given much information about the possible internal symptoms (for example Max's stomach problems).

Jet answered that, although she did receive information about GvHD and other late effects, it is impossible to understand the potential range and severity until you go through it yourself.

Melissa echoed this and mentioned the handbook 'The Next Seven Steps', which was an invaluable source of information and advice. She also spoke about the misleading nature of publicised bone marrow transplantation survival rates, due to the fact that patients of all ages are included in a single statistic.

Mark added that, although there is published guidance on diet and lifestyle for post-transplant patients, you learn over time how to manage things outside of the guidelines based on experience of what a patient can and cannot manage.

Bob Dalgleish commented on the importance of ensuring the children who undergo a bone marrow transplantation have the right level of support in returning to education. Some subjects, such as mathematics, need continuity in teaching and it is imperative that subjects like this are prioritised in the tutoring of young people recovering from a transplant. He recommended that Anthony Nolan make families aware of what subjects should be prioritised in this instance.

Katie thanked Mr Dalgliesh for his recommendation, reiterating that Anthony Nolan's work is patient-led and that the organisation is always open to suggestions on how to better the level of support offered to patients and their families.

Rebecca Roberts commented on the notion that GPs are not knowledgeable enough about the late effects of stem cell transplantation to understand the necessary prescriptions, asking if a reason for GPs seeking clarification was related to a culture of litigation.

Melissa answered that, although she could not explain the motivation behind why some GPs or pharmacists feel uncomfortable giving out repeat prescriptions, she thinks this is because they are trying to double check that a mistake hasn't been made, as this would be unusual in their experience.

Jet agreed, stating that, in her experience, a lot depends on the amount of background knowledge a GP has about the potential late effects of a transplant. Many GPs or pharmacists have never encountered the illness before because of the small numbers affected.

Mark also explained that a nurse at the GP surgery had not understood the relevance of his son's transplant when re-administering Max's inoculations. Instead, they went back to the transplant centre for these.

Katie stressed that the rarity of a bone marrow transplantation means that most GPs will never see a transplant patient. Therefore, due to a lack of understanding about the transplant process, they may be hesitant in prescribing treatments or medicines. She emphasised the need for transplant centre-led education programmes to enable the roll out of shared care arrangements between tertiary, primary and secondary centres.

Jo Taylor asked if this highlighted the need for electronic patient care records, which would make it easy for a doctor to access all the relevant information on a patient's case quickly and easily.

Jet stated that, in her experience, doctors did not pay attention to a letter from the transplant centre explaining her case. Therefore she doubts whether a doctor will pay any more attention to an online record.

Melissa agreed that electronic records may make the information more accessible, however she highlighted that the low probability of a doctor being able to read all the relevant information on a bone marrow transplant patient. It is often easier to explain her case to a doctor rather than wait for them to read all the information on her file.

Ms Taylor asked if a patient-led record, where patients are able to input information into the care summary, would solve the problem.

Katie mentioned treatment summaries, a document patients can hand over to clinicians relating to their condition which are coming in to practice soon. The situation may be slightly different for transplant patients, however, as many are never discharged from care.

Janet Fyle highlighted a project in London looking at GPs issuing repeat prescription for an extended period and offered to enquire as to the results.

Guy Parkes, Head of Stem Cell Donation and Transplant and NHS Blood and Transplant, thanked the speakers for their involvement in the meeting, and promised to pay particular attention to the differing levels of support available for those undergoing a stem cell transplantation who are not classed as a cancer patient. He also found the comment about survival rate statistics particularly interesting.

Guy asked Katie whether this new focus on patient quality of life is a change in strategic focus for Anthony Nolan away from their core activity of providing donors for transplant.

Katie reiterated that patients are at the heart of everything Anthony Nolan does that the charity will never deviate from its core principles. Providing resource to improve patients' quality of life is complementary activity to donor recruitment.

Mark mentioned the importance of Clic Sargent funded nurses to his family, both for clinical support but also someone to talk to that understands all the elements of treatment and recovery.

Guy asked Jet whether her experience to partake in a clinical trial was her decision.

Jet answered that her treatment team had alerted her to the trial in the first instance, and that she made a very easy decision to undergo the treatment.

Pip Parkin noted that, in terms of UK clinical trial recruitment, haematological oncology was at the forefront of research.

Mark asked if there was any other business, thanked all the speakers for their involvement, and ended the meeting.