Education mentoring for teenagers and young adults with cancer

Simon Pini

Abstract
This article provides a review of the unique learning mentor role developed in the Leeds Hospital Teaching Trust since 2004. The role provides educational support to teenage and young adult cancer patients aged 13-25 years. During the period September 2004 – December 2008 the learning mentor has worked with 234 teenage and young adult patients. A questionnaire was administered in the summer of 2008 to gather reflections of patients and professionals, to evaluate the impact of this post. The questionnaire findings support the success of the role and the positive impact it has had for patients and professionals. There is potential for the role to be extended to national teenage and young adult cancer services, and to wider clinical areas where young people are living with chronic illness.

Key words: Adolescent  ■  Chronic diseases  ■  Education  ■  Oncology  ■  Young adult

The generic role of the ‘learning mentor’ developed out of the ‘Excellence in Cities’ initiative in 1999 (Department for Children, Schools and Families, 2009). Learning mentors usually work in educational settings with pupils of all abilities who need help to overcome difficulties that are getting in the way of their learning (Children’s Workforce Development Council, 2009). Since its inception, the learning mentor role has flourished in primary and secondary schools, as well as being introduced to further and higher educational settings. A report by the Office for Standards in Education, Children’s Services and Skills (Ofsted, 2003: p43) found that:

‘Learning mentors are making a significant effect on the attendance, behaviour, self-esteem and progress of the pupils they support… the most successful and highly valued strand of the EiC programme… In 95% of the survey schools, inspectors judged that the mentoring programme made a positive contribution to the mainstream provision of the school as a whole, and had a beneficial effect on the behaviour of individual pupils and on their ability to learn and make progress.’

The Department for Education and Skills (2005) described three main functions of the learning mentor role: to:

- Provide a complementary service that enhances existing provision, to support learning, participation and encourage social inclusion
- Develop and maintain effective and supportive mentoring relationships with children, young people and those engaged with them
- Work within an extended range of networks and partnerships to broker support and learning opportunities, and to improve the quality of services to children and young people.

Development of the learning mentor role in one hospital teaching Trust

In 1998 the Teenage Cancer Trust Unit opened at St James’s Hospital in Leeds, and the Teenage and Young Adult (TYA) service was created to provide peripatetic psychosocial support to TYA oncology patients (13–25 years) in Yorkshire and Humberside. This service, which comprised a nurse specialist and a social worker, was instrumental in advocating for the unit’s patients and their specific needs. In the following 6 years it expanded its staff to include two additional nurse specialists, an activities co-ordinator and a psychologist.

The specific and complex needs of TYA cancer patients were acknowledged in the Platt Report (Platt, 1959, with the recommendation that ‘the problem of adolescents in hospital is a subject that requires special study’). The most recent documentation to recognize the need to address psychosocial aspects of care for TYA patients is the publication by the National Institute for Health Clinical Excellence (NICE) guidance, Improving Outcomes for Children and Young People with Cancer (NICE, 2005). Alongside issues of disease specialism and age-appropriate surroundings, the guidance states that there should be a team on offer who deliver expert psychosocial support. This echoes previous recommendations in the Calman Hinne Report (Expert Advisory Group on Cancer, 1995).

In 2003 the TYA service won the Department of Health ‘New Hope’ award, which provided a sum of money for improving services. In keeping with the philosophy of the TYA service, a focus group was held with patients and families to discuss how to further improve the service offered. The main two themes to emerge were the need for improved
computer facilities and for ward-based support for education. The computer facilities were improved by providing laptops and internet access for each bed space. However, the education improvements were more complicated to address.

At approximately the same time a local charity, the Emma Maltby Memorial Fund, approached the TYA service as it was keen to raise money for TYA cancer patients and was particularly interested in education. Discussion with the service's staff and feedback from the focus group led to the decision to provide one member of staff to help TYA patients with their education. As the patients were under 16 years and because a learning mentor post of this kind would be a national first, it was decided that the support of the local education authority, Education Leeds, would be important. A generic Education Leeds learning mentor job description was therefore discussed and modified with TYA and education staff to address the specialist needs of oncology patients aged 13–25 years.

The learning mentor role was introduced at St James's Hospital in 2004, and is unique to Leeds Teaching Hospital Trust. Initially this was a part-time post covering 25 hours a week, and these 25 hours were funded by the Emma Maltby Memorial Fund. After 6 months it became clear that this role was filling a gap in existing services, as one 19-year old with osteosarcoma explained:

‘The cancer support team all supported me. If it wasn’t for their support I probably would have left my degree course.’

The ever-expanding caseload led to the contract increasing to 37 hours a week, with the extra 12 hours funded by Education Leeds. After the first year Education Leeds agreed to permanently fund the contract if the charity funding ever ceased to be available, thus securing the role. During the subsequent period of September 2004 – December 2008, the learning mentor has provided education support to 234 TYA patients. In the summer of 2008, a questionnaire evaluation was undertaken with service users and staff from the previous year. A postal questionnaire survey was sent out to 75 patients and 10 staff.

Completed questionnaires were received from 29 patient respondents and 10 staff, providing a 39% response rate for patients and 100% for staff. The rest of the article uses quotes from the questionnaire findings to illustrate the benefits of the role.

The role

The main function of the learning mentor role is to provide education support, in its broadest terms, to oncology patients referred to the TYA service. The role needs flexibility to address the wide variety of needs encountered by 13 to 25-year old patients. It is a patient-led service, driven by the individual needs of patients. Each new patient is approached without preconceptions and their issues are dealt with as unique and specific to them. One 21-year old with acute lymphoblastic leukemia described the piece of mind the mentor provides:

‘It was enough getting over the shock and diagnosis and treatment without having to worry about college and good to know that the learning mentor was able to take over.’

The learning mentor role is based in the TYA service, but has developed into an integral part of the multidisciplinary teams (MDTs). The learning mentor attends weekly psychosocial meetings with health and education professionals, as well as arranging and facilitating meetings in each patient’s school. One 16-year old with acute lymphoblastic leukemia noted the improvements made by this MDT working:

‘The learning mentor and liaison nurse explained aspects of my treatment and helped alter my timetable to suit me better.’

A 15-year old with Hodgkin's lymphoma also noted:

‘It was really helpful because all the teachers understood if I wasn’t there and helped when I was.’

MDT working is a crucial function of the role as it allows the learning mentor to be well-informed about patient progress and assess the appropriate timing of interventions. As well as keeping up to date with each patient’s health circumstances, MDT working allows the learning mentor to promote education as an important issue among staff and offer a different perspective to holistic care. One consultant paediatric oncologist highlighted how important this MDT collaboration is:

‘As a professional, of whatever hue, it is useful to receive feedback from patients and families. Our patients often speak with the mentors and provide them with important feedback on how we are all performing.’

A clinical nurse specialist also noted the positive impact of the mentor role on the MDT:

‘Patients/staff/parents all now see education as been a normal part of their daily routine whether at home or in hospital.’

The learning mentor duties

The specific interventions can be extremely diverse but the main duties are outlined in Table 1, with corresponding questionnaire responses which illustrate how each duty benefits patients. Within these categories there are many possible tasks, which can range from arranging a GCSE examination in hospital to discussing contracts with a patient’s university landlord. In all of these situations the learning mentor is working as an advocate for the patient and has their needs central to all plans.

The learning mentor role is not tied to school term times. This means that the mentor will work in the holiday periods when schools, colleges and universities are closed; as one 16-year old patient diagnosed with acute lymphoblastic leukemia during a summer holiday period explained:

‘I met [the learning mentor] within a few days of being admitted. I found him approachable and easy
to talk to. He made me realise that I could carry on with my education alongside my treatment.’

During these out of term times the role has additional functions. There is the opportunity for the mentor to be involved in research in the department or to contribute to wider projects being conducted by agencies such as the Teenage Cancer Trust. Enrichment activities can be offered by the mentor in these periods and there have been several successful projects in Leeds in areas including photography, animation, creative writing, short film making and audio drama. These projects enlisted the help of specialist tutors and were arranged and facilitated by the mentor.

The mentor works with, but is not embedded in, the hospital school system. The aim of this position is to take a long-term approach to education support for this group of young people. Patients are not officially discharged from the mentor’s case load until they are 5 years post-treatment and even after this time the mentor can offer ‘sign-posting’ to professionals working with long-term survivors of cancer.

In terms of improving the service, the respondents provided some valuable insight:

‘Perhaps more support with what to do after treatment’
‘There should be home tuition available for college students. This stage of education is important and makes life more normal if you can continue’

Further developments
From February 2007, two new learning mentors were added to the hospital and home teaching service in Leeds. The first of these is allocated to the 4–13 year old oncology patients and is very similar to the TYA mentor role. The second mentor has the remit to work with patients aged 4–16 years with a brain tumour or acquired brain injury. This role developed following the identification of the particular and long-term needs of both patient groups, as well as the fact that they regularly access distinct neurological MDTs. Both of these roles developed out of the success of the TYA mentor and are being successfully applied to their specific areas.

Conclusion
This article has outlined the development and implementation of a unique learning mentor role for TYA patients with cancer at one hospital teaching trust in Leeds. User feedback from a questionnaire conducted in 2008 demonstrates how this role has benefited these patients. There is clear potential for the TYA mentor

### Table 1. Main duties of learning mentor

<table>
<thead>
<tr>
<th>Duty</th>
<th>Questionnaire responses</th>
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<tbody>
<tr>
<td>Liaison between patients and their main places of education</td>
<td>‘The learning mentor got in touch with college, asked them to send me work and explained my situation.’ – A 17-year old with Hodgkin’s lymphoma.</td>
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<tr>
<td>Liaison between patients and supportive services e.g. Hospital schools, Home tuition, Connexions and Careers</td>
<td>‘It was brilliant. He was the best teacher ever.’ – A 15-year old patient describing her home tutor</td>
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<tr>
<td>Course and career advice</td>
<td>‘The learning mentor made research on my behalf for Open University.’ – A 19-year old with acute lymphoblastic leukemia</td>
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<td>Personal and professional development with patients</td>
<td>‘Apprehensive of my illness and what it would mean. Cancer makes one a bit too ‘different’ from other people!’ – A 21-year old with Hodgkin’s lymphoma commenting on her friend’s approach to her support</td>
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<tr>
<td>Being an advocate for patients</td>
<td>‘I had help from the learning mentor, he makes me feel more confident about going back to college in September’ – An 18-year old with Hodgkin’s lymphoma</td>
</tr>
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<td>Devising and implementing appropriate education plans</td>
<td>‘The learning mentor helped me a lot to choose my options and decide what paths and decisions were best for me. Also, when I was up to it, the hospital teachers gave me work to do’ – A 13-year old with osteosarcoma</td>
</tr>
<tr>
<td>Arranging work placements and voluntary work</td>
<td>‘Outside of the hospital he arranged 3 days of work experience at Yorkshire Television on my behalf, in the post-production department ... it made me feel comfortable (like I’ve made the right choice) continuing my interest in film and media.’ – A 21-year old with congenital erythropoietic porphyria</td>
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<td>Meaningful plans for the future</td>
<td>‘The engagement of the learning mentor in working to the future must re-enforce the hope that we as clinicians express for cure (or at very least, a period of meaningful survival)’ – Consultant paediatric oncologist</td>
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role to be undertaken in teenage cancer units nationally. The flexible working model of the learning mentor role facilitates its application to new areas, including other chronic disease groups. Education is increasingly being recognized as an important component of the holistic care of young people (NICE, 2005) and can be more comprehensively addressed by having a designated member of staff in the health MDTs. One 19-year old with osteosarcoma illustrates the importance of the TYA service as a whole, including the learning mentor. This patient had considerable support from the LM role, as well as a social worker and nurse specialist:

‘Life seems worthless when you find out about an illness like this. All the nurses and the hospital staff, everyone on the ward were great. Ward 10T [TCT Unit] is excellent. You feel so supported and you get through the illness with the support. They are there for everyone, for the whole family.’


Available at: http://www.standard.dfes.gov.uk/studysupport/impact/eics/ (accessed 7 November 2009)

**KEY POINTS**

- Teenage and young adult oncology patients need education support from diagnosis into follow-up.
- The learning mentor role provides education support for 13–25 year olds.
- The learning mentor role has been received well by patients and staff.
- The learning mentor needs to be integrated into health and education multidisciplinary teams to provide the most comprehensive and informed support.

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