Rennie Grove Hospice Care
Care based around you

Transition Statement: Young people moving to adult palliative care services

Transition to adult services is a "purposeful, planned process that addresses the medical, psychological, educational and vocational needs and of adolescents with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems." (Blum RW et al 1993, cited in Together for Short Lives, 2015)

We recognise and understand that the model of service provision is very different in children's and adults' palliative care, with children's palliative care support being offered from point of diagnosis, throughout the child's death and beyond. We offer support at transition to young people and their families to help them understand what services are available in adults' palliative care and the differences in their roles and remits..

At Rennie Grove Hospice Care we are committed to ensuring that each young person and their family feels supported throughout the process of transitioning to adult services. We recognise that every young person who receives care from our service has different needs, requires and receives different and complex medical, social care and education and therefore each will have different and fluctuating needs. Most importantly each young person will have their own unique aspirations.

Within the Children's Hospice at Home Service there is a Transition Lead. This role includes ensuring that each young person is aware of the adult services available in their geographical area for their specific needs and that each young person and their family understands the statutory processes around moving to adult services.

We will work as an integral member of the team around the young person and we will ensure that, whatever our identified role, transition planning is person-centred and that the voice and views of the young person are central to planning and decision making. We uphold the philosophy of *'Nothing About Me Without Me'*. Our role is to advocate for young people and their families and ensure that even young people with impaired communication skills are listened to.

Our role includes supporting and empowering adult services to be able to meet the needs of young people, and this includes enabling the family and children's services to develop robust care planning documents and to train adult services in new skills that they may require to meet the increasing complexity of need. We will support the use of current documents including Education and Health Care Plans, the Together for Short Lives Checklist for Transition and My Care Transfer.

While a young person is receiving a service from Rennie Grove's Children's Hospice at Home Team we will ensure that care delivery is person-centred and that adolescence is acknowledged as a distinct stage in a young person's development. As well as meeting a young person's health needs, we will ensure that they can participate in education and social activities. We acknowledge that young people with life-limiting conditions can be isolated. Our staff will be trained and empowered to explore with the young person their

aspirations and fears. This includes our commitment to enabling discussion on areas of development including sexuality.

At the point that a young person requires end-of-life care, this will be provided collaboratively with other hospices and statutory services enabling the young person to have choice as to place of care and place of death. On receiving a referral for a young adult 17-19 years, care will be provided by either the Children's or Adult Hospice at Home Service or the two services jointly. Again this will be patient-centred and have the young person's and the family's needs and views at the centre.

References

National Institute for Care and Excellence (2016) Transition from children's to adults' services for young people using health or social care services. Available from: https://www.nice.org.uk/guidance/ng43

Together for Short Lives (2015) Stepping Up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions. Available from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/02/ProRes-Stepping-Up-Transition-Care-Pathway.pdf