A Hospice Approach to the Management and Support of Young People with Issues Relating to Sexuality for Young People with Palliative, Life Limiting and Life threatening conditions

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Young People and sexuality – Points to Consider

• All young people have the right to receive information and support to develop their self-esteem, a positive body image and self-confidence in relation to their sexuality and relationships.

• This can be particularly challenging for young people with life limiting conditions or complex health conditions and their parents / carers.
• Professionals should recognise that avoidance of issues around sex and sexuality can cause deep unhappiness and distress.

• Sexuality is not just about sex and sexual partners. Behaviours, the way we dress, friendships and relationships with other people are important. Friendships can be a key part of growing up - friends can help you understand what they value about you and how special and unique you are.

• Parents and carers may find that when a young person with a palliative care condition reaches puberty it can feel like an empty or purposeless state. Sometimes the situation is very distressing - it may bring to the fore, fears that they will never be a grandparent, or that the young person will not grow up having a physical relationship, never have a partner.
• Managers and organisations should work towards achieving a culture in which sexuality issues can be openly discussed within the team, and that young people are encouraged and supported to talk about their sexuality and sexual needs.

• Support should be provided to help young people develop skills such as decision making; communication; assertiveness and understanding personal safety to underpin their ability to develop relationships.

• Wherever possible they should be assisted to understand their sexual feelings and learn about acceptable and appropriate behaviour and respect for others.
Clinical Governance

• Clinical Governance considerations underpin, sustain and improve high standards of care. The CQC and RCN suggest 5 key considerations:
  • **Young People** – how support around sexuality is based on individual’s needs.
  • **Information focus** – how sexuality information is discussed and presented.
  • **Quality Improvement** – how these sexuality standards will be reviewed and attained.
  • **Staff focus** – how staff are supported to address issues of sex, intimacy and relationships.
  • **Leadership** – how improvements can reduce taboos and improve knowledge and confidence in staff.
A hospice Approach to Managing Issues Relating to Sexuality

KEY POINTS:

• Addressing issues about sex and sexuality is both appropriate and legitimate, and there is a professional and clinical responsibility to do so.

• Issues relating to sex and sexuality are most appropriately addressed within a wider context of health and well-being, including sexual health.

• All young people should be able to enjoy and control sexual and reproductive behaviour with freedom from fear, shame, guilt and false beliefs.
• If individual professionals feel uncomfortable in supporting young people with issues around sex and sexuality it would be in no party’s best interests to insist that they participate in this aspect of personal care.

• Professionals who feel strongly about this should inform colleagues, their manager and the person receiving care that they have a conscientious objection to a particular procedure and arrange for a suitably qualified colleague to take over responsibility for that person’s care.
ROBUST POLICIES:

• Identify clear processes and clear reporting lines.

• Fit within legal frameworks.

• Be informed by evidence and research.

• Identify a named person/individuals to lead on sexuality who can be responsible for supporting staff members.
Moving Forwards Within the Hospice

KEY ACTIONS:

• The hospice has developed a policy, processes, training and guidance that establish clear boundaries for staff dealing with issues relating to sexuality, intimacy and relationships, including identification and management of potential abuse/ safeguarding issues.

• Key individuals have been identified as ‘Sexuality Champions’ and will be flagged to young people and families as professionals with additional expertise in supporting this aspect of care. These individuals have undergone dedicated training in relation to legal issues, emotional resilience and practical support, and will received bespoke clinical supervision.
• Training is being delivered so that care staff feel supported to develop the skills, either to provide safe support or signpost to a more specialist service.

• The training will ensure that staff are knowledgeable of developmental stages, social, emotional, psychological and physical development; and that staff understand young people as individuals and take account of their interests and past experiences.

• It will cover a whole range of issues relating to communication with young people and families and practical support including intimate care, use of trained sex workers, clinical scenario’s and safeguarding.
• Young people and their families are being made aware of the policy, processes and support available, and they will be consulted about ongoing needs or concerns.

• Support will be offered to families who struggle to understand the reason for this work.

• There will be ongoing review of needs – of young people, families and staff to ensure that the policy remains robust and fit for purpose.
Thank you for Listening...

Any Questions?