

Transforming care for young adults with complex and life limiting conditions

ECHO Transition Partnership Manager, HUK





Adolescents and Young Adults

Many children and young people with palliative care needs who could benefit from palliative care services remain unrecognised by service providers.

In particular young people age 14 to 25 years tell us that their palliative care needs are frequently not picked up or not met when they transition to adult services.

(Noyes et al 2014)



Six key elements for creating a good transition process

1. Recognise and **discuss individual needs in young people friendly terms**
2. **Look at transition holistically**, to include advice on: social, emotional, educational, geographical, employment, relationships and physical health
3. Adult services to make **social connections** and have a long term relationship with young people, to **provide continuity of care**
4. **Multidisciplinary teams are important** and should meet regularly to prepare the young person for transition
5. Signpost to **local services, resources and knowledge**
6. Support young people with their **mental health**

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Introduction to Project ECHO



Transforming care for Young People with complex and life limiting conditions

Hospice UK, three year project - update:

- Employed **ECHO Transition Partnership Manager**
- **Project ECHO Hub training** for three organisations (Keech Hospice, Solent NHS and Yorkshire and Humber Children's Palliative Care Network)
- Membership at **Burdett National Transition Nursing Network** - Advisory Group
- Stakeholder – **relevant NICE Guidance**
- Dissemination of **Transition Research**
- Supporting the development of **Transition Knowledge Networks**
- Working closely with colleagues at Together for Short Lives bringing together a range of professionals via **Transition Community of Practice (COP)**
- Facilitation of Bi Monthly **Transition Coordinators meetings**
- Developing an online **resource, evaluate** and produce **guidelines/ recommendations**





Project ECHO Transition Hub Sites - reach

- **Yorkshire and Humber Children's Palliative Care Network (YHCPCN)**. Partners for the YHCPCN hub are Leeds Teaching Hospital Trust, Sheffield Children's Hospital NHS Foundation Trust, Bluebell Wood Children's Hospice, Forget Me Not Children's Hospice, Lindsey Lodge Hospice, Martin House Children's Hospice and St Andrews Hospice and St Luke's Hospice
- **Keech Hospice** – Adult Hospice for Luton and south Bedfordshire, and the Children's hospice for Bedfordshire, Hertfordshire and Milton Keynes
- **Solent NHST** – prior involvement with NHS I/E Transition Collaborative



Project ECHO session topic - examples

- NICE Guidance for Transition
- Transition Pathways – how they should work
- Mental Capacity Act/ Deprivation of Liberty
- Complex Needs Prevalence Data (up to 25 years)
- Gaps in transition - Falling into the abyss
- Sexuality Alliance, Let's talk about sex

Project ECHO Participation

- Parent/ Carer representatives
- Young Adult/ Lived Experience
- Children's and Adult Hospice/ Palliative Care Services
- Children's and Adult Social Care
- Continuing Health Care Colleagues
- Doctors – various specialities
- Allied Health Care Professionals
- Registered Nurses (hospice/ non hospice/ NHS)
- Schools and Colleges



Safe
Listening
Affirming
Respect
Support
All teachers
All learners



National Transition Community of Practice



I am finding the meetings really helpful. It feels good to know how many people there are out there who have so much experience.

I think these meetings are so important; without them I think knowledge and information would get lost.

There are so many people doing incredible work in the world of Transition but it is only through meetings like this do we get to hear about them. I really appreciate being part of them.

I am looking forward to future coordinators meetings I found the first one (attended) very informative.

I found yesterday's meeting really helpful. Such a wealth of experience and enthusiasm for the transition process.

The Community of Practice really feels like it is developing into something of a new season.



Quarterly Together for Short Lives/ Hospice UK Joint Communications

[View this email in your browser](#)



Hospice UK and Together for Short Lives have streamlined communications to ensure that news and updates are provided in a joined up way. We have set up a new Transition Community of Practice and members of this group will all receive this new look, joint bulletin on all things transition.

[Please share the link for registrations](#) with colleagues who might be interested.

