



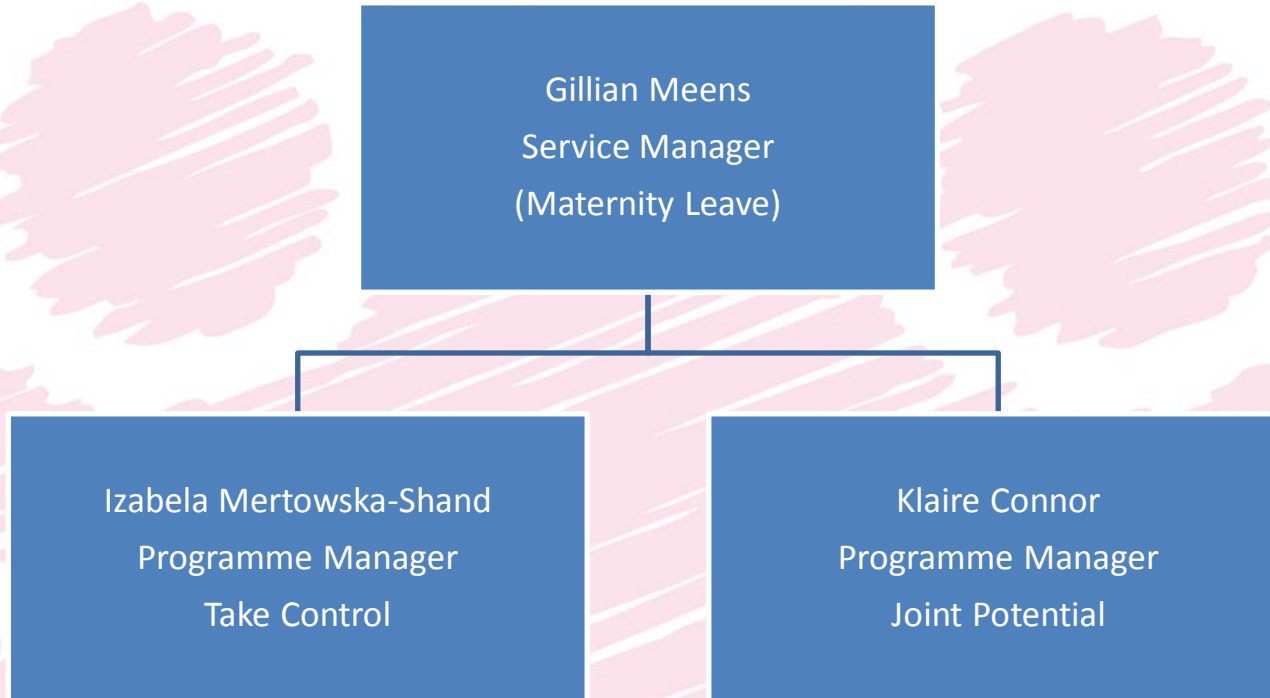
ARTHRITIS CARE

Arthritis Care Scotland

Young People and Families Service

Klaire Connor - Joint Potential

Staff / project structure



Joint Potential



ARTHRITIS CARE

- Running since 2009
- For 16 – 25 year olds from across Scotland
- FREE to participants
- JP+: Monthly session in Rheumatology units
- Residential weekends
 - Activity Weekend
 - Self-Image Weekend
 - Positive Future
 - Moving On, Moving Up
 - Good Relationships
- One day workshops
 - Wellbeing
 - Sex: Facts and Fertility
 - Pain Management



Joint Potential (Plus)



ARTHRITIS CARE

- Variation across Scotland – different ages, timescales for discussion and planning and different experiences – some very positive, some less so
- Both parents and young people (even those that had good experiences) identified it as a time of anxiety and worry
- General feeling of lack of communication between paediatric and adult services – request for transition professional
- Gap for those that have been diagnosed at 15 / 16 yrs old – no time for transition planning yet



Transition in Scotland – Patient Perspective



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- “I thought I was well prepared but it was a lot different from what I thought it was going to be, I thought it was going to be the same.” “I wish they had been more honest.”
- “It wasn’t a transition just from one step to the other.”
- “I wish I had met the adult doctors before I moved.”
- “I wish the children's and adult doctors had been in the same room at the same time. I have a bad needle phobia and that info wasn’t passed on to the adult doctors.”
- “It was scary at first but I had plenty of time to ask any questions I had.”
- “I was worried about something going wrong, it wasn’t something I had ever done before.”

Transition in Scotland – Parent Perspective



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- “I worry about my daughter not complying with taking her medication once she has transitioned and I have less control.”
- “I find it hard to relinquish control even though I know I need to. You are never told how hard it is going to be.”
- “It is an unsettling time as it is a time of change anyway with leaving school and looking at college / uni options.”
- “It needs to be seamless.”
- “Sometime I don’t think they realise how much both the parents and young people are psychologically affected.”
- “We have only just started talking about it but I am confident they will have it all in hand.” “It will be a real challenge breaking the relationships with the paediatric staff to move.”
- “There is a lack of support for parents.”



ARTHRITIS CARE

A little about me...

Sex



ARTHRITIS CARE

- **Myths and misunderstandings**
- **Medications – Long term effects**
- **Young peoples opinions**
- **Medication**



Drugs & Alcohol

- **What is not talked about!**
- **What we need to talk about!**
- **Young peoples perspective**
- **Consultant perspective**

Questions.



ARTHRITIS CARE





Klaire Connor,
Joint Potential

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