

Mothers help young people with arthritis through the tough times

March 16 2015, by Jane Tadman

Young people with arthritis rely heavily on their mums for support during times of change and uncertainty – despite claiming to be independent, according to new research from Arthritis Research UK.

Young people with inflammatory arthritis have to make tough decisions about whether to take powerful drugs that they may have to remain on for the rest of their lives.

But while they claim that they make these decisions themselves, new research from Newcastle University and published in *Rheumatology* reveals that their mothers 'played a particularly prominent role, providing cognitive practical and emotional support' and had a considerable influence on their sons' and daughters' treatment decisions. Partners played a much less important role in young people's network of relationships.

"Young people with <u>inflammatory arthritis</u> can have severe disease that warrant biological therapies," explained Ruth Hart, lead author of the paper. "While these drugs can offer considerable short-term benefits, there are short-term risks and the long-term consequences remain uncertain, and this is of particular concern for those who begin taking them early in life.

"Young people offered biologics are confronted with a decision which may have profound consequences at a point when their disease is at its worst and their lives are characterised by change and uncertainty."



It was clear that while young people claimed they made their own decisions about treatment, the study found that mothers often remained involved in a wide range of ways well into early adulthood, particularly – but not exclusively – where their son or daughter was diagnosed as a child.

The study found that mothers made appointments, took young people to hospital to hospital, ordered medication and prepared and administered injections. They also asked questions about drugs, did research, and discussed the pros and cons of treatment with their son or daughter.

"Mothers additionally offered emotional support to confront an important decision at a difficult time, essentially 'being there' for young people, and providing reassurance, comfort and encouragement," added Ms Hart, from Newcastle University Institute of Health and Society.

A simple but important message from the research is that decisions are facilitated by and may depend upon the support of others, in particular mothers, said Ms Hart, and information and education for decision-making needed to explore and take into account these important relationships. Being clear about who is involved in decision-making is important for health professionals if they are to help young people become independent at a pace appropriate to their individual needs.

The qualitative study involved young people aged 16-25 from three NHS hospital trusts. Twenty-five were interviewed plus 11 'trusted others' such as mothers, and six <u>health professionals</u>. Mothers featured prominently in stories of making and enacting decisions in around three-quarters of cases. The majority of these young people were living with their mother at the time of the research.

Provided by Arthritis Research UK



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