

# Maternity care for pregnant women with Ehlers-Danlos syndromes must improve, researchers say

April 5 2018

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Maternity care for pregnant women with Ehlers-Danlos syndromes "must improve," researchers say.

A study by academics at Coventry University has found a lack of awareness among midwives and health professionals of the [conditions](#) and the number of risks that women with them face during pregnancy and birth.

They are concerned that this could lead to delayed access to appropriate care – and have serious consequences for the mums-to-be and their babies.

Ehlers-Danlos syndromes (EDS) are a group of inherited conditions that affect connective tissues in skin, joints, blood vessels and internal organs.

They can result in symptoms including: hypermobility (an increased range of joint movement), stretchy skin and fragile skin that breaks or bruises easily.

It has been estimated that at least one or two people in 100 have EDS, but that only 1 in 20 people with the syndromes have been diagnosed.

The conditions can also cause health problems for women during birth

and for their newborn babies.

Risks for [pregnant women](#) include: premature or rapid labour, problems with anaesthesia, bleeding, tears during birth, heart problems, unstable joints and poor healing.

The Coventry study is the first review to draw on the current evidence and research into the condition and use this to explore midwifery care concerns, given that there are no guidelines for the management of pregnancy and labour for women with EDS.

Researchers Dr. Sally Pezaro, from the university's School of Nursing, Midwifery and Health, and Dr. Gemma Pearce, from its Centre for Advances in Behavioural Science, worked with GP Emma Reinhold, a primary care advisor for EDS UK.

They stressed that midwives must work in partnership with a multidisciplinary team, including obstetricians, anaesthetists and GPs to ensure women achieve the most appropriate care plans.

They said midwives have an 'important role' to play in a multidisciplinary approach to caring for women with EDS by providing routine care, identifying and reducing risk, making swift referrals where appropriate, supporting individualised care and educating colleagues, pregnant women and the wider public.

As midwives have regular contact with women during pregnancy they may be ideally placed to raise the possibility of EDS in undiagnosed patients

Identifying the diagnosis before giving birth should enable the most appropriate decision-making in collaboration with women and their families, the researchers said.

Better guidelines relating to the condition would also give an opportunity for [health professionals](#) to understand, raise awareness, and more effectively support undiagnosed pregnant women and those suspected of having the condition, as well as those who already have a diagnosis.

The research has been published in the *British Journal of Midwifery*.

Dr. Sally Pezaro, who led the research, said:

"Complications associated with Ehlers-Danlos syndromes during pregnancy and birth can be significant. A midwife's awareness of the condition and its impact upon pregnancy can not only instigate more timely and appropriate referrals but also improve the quality of any professional advice given.

"There are currently no guidelines for caring for or treating childbearing women with the condition.

"We feel improvements are needed to make sure women have access to [maternity care](#) plans that don't just involve [midwives](#), but also obstetricians, anaesthetists and GPs.

"Midwives have an important role to play in this team approach to caring for pregnant [women](#) who have EDS to ensure that the birth of their child is an amazing moment in their lives and reduce the risk of potential complications."

**More information:** Sally Pezaro et al. Hypermobility Ehlers-Danlos Syndrome during pregnancy, birth and beyond, *British Journal of Midwifery* (2018). [DOI: 10.12968/bjom.2018.26.4.217](https://doi.org/10.12968/bjom.2018.26.4.217)

Provided by Coventry University

Citation: Maternity care for pregnant women with Ehlers-Danlos syndromes must improve, researchers say (2018, April 5) retrieved 12 May 2024 from

<https://medicalxpress.com/news/2018-04-maternity-pregnant-women-ehlers-danlos-syndromes.html>

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