Women living with CKD

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Overview

About this Document

A supportive resource for women living with chronic kidney disease (CKD), bringing together key information and useful links from the webinar on family planning and decision-making. Designed to help women feel informed and supported when exploring their reproductive choices and discussing family planning with their healthcare team.

Previous Webinars

To watch our previously held webinars on topics such as; home dialysis, holiday dialysis, diet and nutrition, and current research.

www.kidneywales.cymru/webinars

Click here for our YouTube Channel.



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Introduction

"Women with kidney disease told us they didn't always know what questions to ask about pregnancy, fertility and having children. So we created something to help."

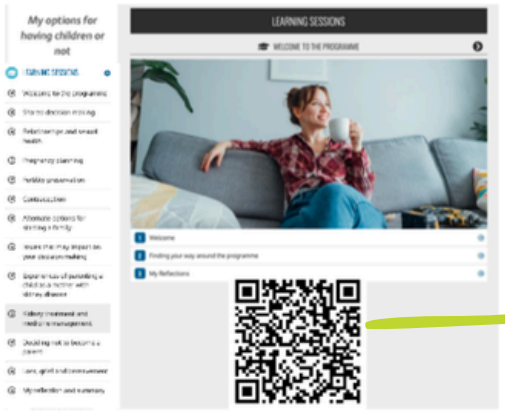
For women living with kidney disease, decisions about pregnancy and having children can be complicated, deeply personal and sometimes overwhelming. UK-wide research undertaken by Dr Leah McLaughlin found that many women felt unprepared, lacked the information and support they needed, and did not always feel that their own priorities and life goals were part of the conversation.

Dr McLaughlin and her team wanted to change that.
They have produced a new, free online shared decision-making resource for women with kidney disease, developed with women themselves, healthcare professionals and organisations working across kidney health, pregnancy, fertility and family-building.
The resource brings together real women's experiences, trusted information and practical tools to help women explore their options, think about what matters most to them, record their questions and concerns, and prepare for conversations with their healthcare team.

My Options for Having Children

A new shared decision making module to help women with kidney disease think about their options and choices.

Scan the QR code or click on the link to sign up and to be taken to the module.



www.mydesmond.com/app/register/my-options-for-having-children-or-not

SCAN HERE

Further information including the research underpinning this resource can be found here: https://kidneyresearchunit.wales/impact-case-studies.htm?id=34

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Introduction

Dr Leah McLaughlin is a Senior Research Fellow at Bangor University and a Health and Care Research Wales Advanced Fellow. She is a health services researcher whose work focuses on improving how patients and families are supported to make complex and highly personal healthcare decisions.

Leah supported a UK-wide programme of research exploring reproductive health, pregnancy, parenting and shared decision-making among women living with kidney disease. Working with women with kidney disease, healthcare professionals and partner organisations, this research has informed the development of the new shared decision-making resource being launched at Women Living with CKD webinar

Leah's current research, focuses on how parents and families are supported when making decisions about organ donation following the death of a child. Her wider research interests include organ donation and transplantation, shared decision-making, patient and public involvement and developing health services around the needs and priorities of patients and families.
The women and kidney disease programme is now moving into its next phase, led by PhD researcher Raquel Ron Parralejo, who will also be introduced during the webinar.

Further information is available here:

https://kidneyresearchunit.wales/impact-case-studies.htm?id=34



Presenter, Leah McLaughlin
Research Team, Sian Griffin Cardiff and Vale UHB, Jane Noyes Bangor University, Mathew Graham Brown Leicester University in collaboration with the MyDesmond development team
College of Medicine and Health's: Women's Health Symposium Wednesday 17th September 2025

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Caerdydd a'r Fro | Cardiff and Vale University Health Board
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Questions to ask your kidney team

Pre-Pregnancy & Timing

What is my current stage of CKD and individual risk level?
Ask how your eGFR, blood pressure, and protein levels translate into specific risks for a pregnancy, or whether a risk-prediction tool applies to your case.

Is now the right time, or should I wait? Discuss whether you should time pregnancy sooner while function is strong, or wait (such as waiting at least 6 months after a lupus nephritis flare or 1 year following a kidney transplant).

How will pregnancy affect my long-term kidney function? Inquire about the expected rate of decline and whether pregnancy might accelerate your timeline for dialysis or a transplant

Medication & Health Management

Do any of my current medicines need to be changed or stopped?
This might include medications like ACE inhibitors, ARBs, and SGLT2 inhibitors

Do I need specific supplements or preventative prescriptions?
Ask about starting folic acid (and higher doses if you have a transplant), vitamin D, or low-dose aspirin to lower pre-eclampsia risks.

How will my blood pressure and protein leakage be managed?
Clarify target blood pressure ranges and how proteinuria will be monitored safely during pregnancy.

Care and Support

Will I have a multidisciplinary team?
Ask how your nephrologist, obstetrician specialising in high-risk pregnancies, and renal dietitian will coordinate your care

What monitoring will I need during and after birth?
Find out how frequently your blood and urine will be checked, and what extra support or contraception is recommended post-delivery.

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Helpful Resources

Kidney Care UK
Download or order a copy of Kidney Care UK's **Pregnancy and chronic kidney disease** booklet. The booklet is aimed at pregnant women with CKD, or those who are considering becoming pregnant.

https://kidneycareuk.org/get-support/free-resources/patient-information-booklets/pregnancy-and-chronic-kidney-disease/

Women's health and chronic kidney disease
There is also a booklet is about how CKD affects women in particular and also how certain aspects of women's health can affect CKD.

https://kidneycareuk.org/get-support/free-resources/patient-information-booklets/womens-health-and-chronic-kidney-disease/
Call on 0808 801 00 00 or email support@kidneycareuk.org.

PKD Charity
Information for women with autosomal dominant polycystic kidney disease (ADPKD) who are pregnant or planning a pregnancy. It's also for their partner, family and friends. It explains the care you should receive when pregnant with ADPKD to keep you and your baby safer.
Their helpline is available on 0300 111 1234, and by email on info@pkdcharity.org.uk

https://pkdcharity.org.uk/adpkd/life-with-adpkd/adpkd-and-pregnancy?eprivacy=1

UK Kidney Association (UKKA)
Provides detailed clinical and patient information breaking down risks by CKD stage (Stages 1 through 5), expected early delivery rates, and management strategies

https://www.ukkidney.org/rare-renal/patient-information-0/pregnancy-and-chronic-kidney-disease

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Helpful Resources

Kidney Wales
The Kidney Wales Patients and Supporters Community Group is a closed Facebook group offering a safe, supportive space for people affected by chronic kidney disease. It's a place to connect with others who understand, share experiences, and offer encouragement along the way.

Whether you're looking for reassurance, shared understanding, or simply a friendly conversation, you'd be very welcome to join our community.
https://www.facebook.com/groups/KidneyWalescommunity/

Diabetes UK Cymru
They support people in Wales with diabetes by raising awareness, improving care, and providing local help, support, and information.
Call 0345 123 2399 -Monday to Friday 9am to 6pm or e-mail wales@diabetes.org.uk

https://www.diabetes.org.uk/support-for-you/diabetes-uk-in-your-area/wales

Engaging and supporting women with chronic kidney disease with pre-conception decision-making (including their experiences during COVID 19): A mixed-methods study protocol, https://pubmed.ncbi.nlm.nih.gov/33656192/

Interventions for and experiences of shared decision-making underpinning reproductive health, family planning options and pregnancy for women with or at high risk of kidney disease: a systematic review and qualitative framework synthesis, https://bmjopen.bmj.com/content/12/8/e062392

Feminizing care pathways: Mixed-methods study of reproductive options, decision making, pregnancy, post-natal care and parenting amongst women with kidney disease,https://onlinelibrary.wiley.com/doi/full/10.1111/jan.15659

"It was classed as a nonemergency": Women's experiences of kidney disease and preconception decision-making, family planning, and parenting in the United Kingdom during COVID-19, https://pubmed.ncbi.nlm.nih.gov/38485661/

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Helpful Resources

From "Women don't know what they don't know" slide

Adapting interventions to new contexts—the ADAPT guidance
www.bmj.com/content/374/bmj.n1679

https://pubmed.ncbi.nlm.nih.gov/37833123/

https://pubmed.ncbi.nlm.nih.gov/31660965/

https://www.leicesterkidneylifestyle.team/my-kidneys-me-resources

http://www.kidneyresearchunit.wales

www.mydesmond.com/app/register/my-options-for-having-children-or-not

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