

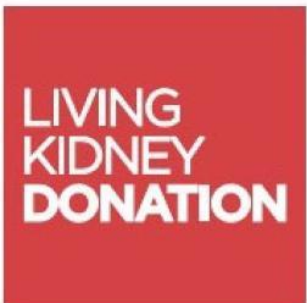
How and when to engage living donors?

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UK LKD Network Meeting, Birmingham

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How and when to engage living donors?

- Background & Renal Education and Choices @ Home (REACH) pilot
- Promoting a Transplant First approach – preparing recipients and potential donors
- When to engage potential donors? Rationale & Team effort
- How to support recipients to engage potential donors? Ideas & Team effort
- Summary

REACH pilot

- Home education about living donor kidney transplantation for potential recipients, along with members of their support network
- Based on successful Dutch model “Kidney Team at Home”
- To date, approximately 150 home visits undertaken
- Evaluation indicates that RRT knowledge significantly improved after home visit
- Feedback from patients and their invitees overwhelmingly positive
- Now considered standard care in NHS Lothian
- REACH Transplant to be rolled out across Scotland

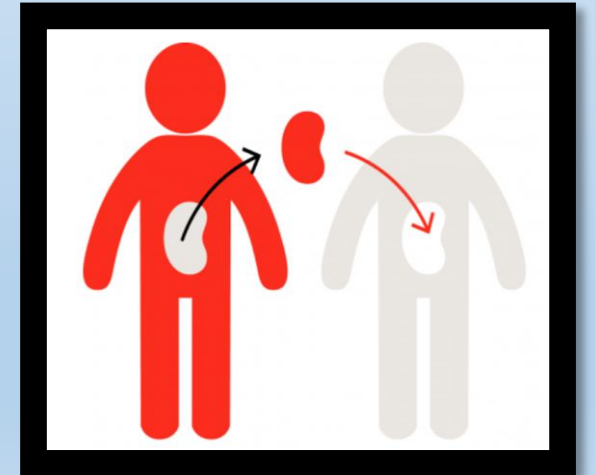




"Living donor kidney transplantation is considered the gold standard treatment for end stage kidney disease. Pre-emptive and early transplantation confers advantages..."



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Preparing recipients and potential donors

When to engage potential living donors?

- Assessment of potential living donors can take many months, or even longer – often multiple donors need to be assessed
- Need to start assessment process sufficiently early that donor is ready to donate at the point where the patient is roughly six months from needing dialysis
- Preparation of patients and donors is required before this – complex information – time required to absorb this and act
- Without this preparation, inequality of access is built into the system
- Whole process needs to begin around the time that it becomes clear that RRT is likely to be required in the next two years and that patient is likely to be a suitable transplant candidate
- What can we do to make this happen? Team effort



Kidney Care

In the UK, guidelines recommend that all patients with stage 5 chronic kidney disease (eGFR <15) be assessed and placed on a waiting list for kidney transplantation if judged to be within six months of their anticipated dialysis start date.

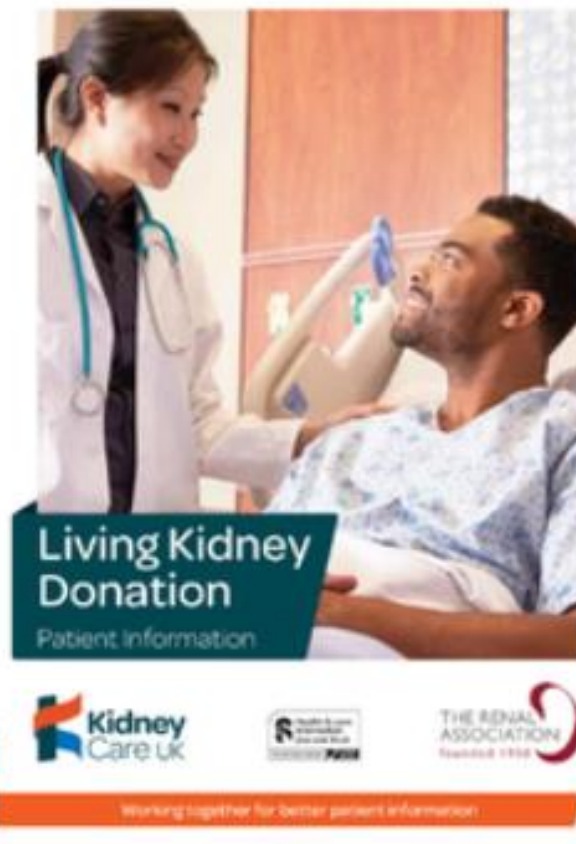
Assessment should start earlier (when the eGFR is approximately 20) where live donor transplantation is being considered.

Timely listing for kidney transplantation: A summary of the literature

January 2012

How to engage potential living donors?

- Many patients find this extremely difficult
- Preparing patients with a Transplant First approach can help
- Some patients appreciate help with how to broach the subject
- Other patients need different support e.g. reluctant recipient
- Is there a patient advocate? How can we engage them and support them?
- What resources can we use?
- Signposting to high quality, reliable information – incl peer support



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INFORMATION FOR PEOPLE WHO MAY NEED A KIDNEY TRANSPLANT IN THE FUTURE





About kidney health

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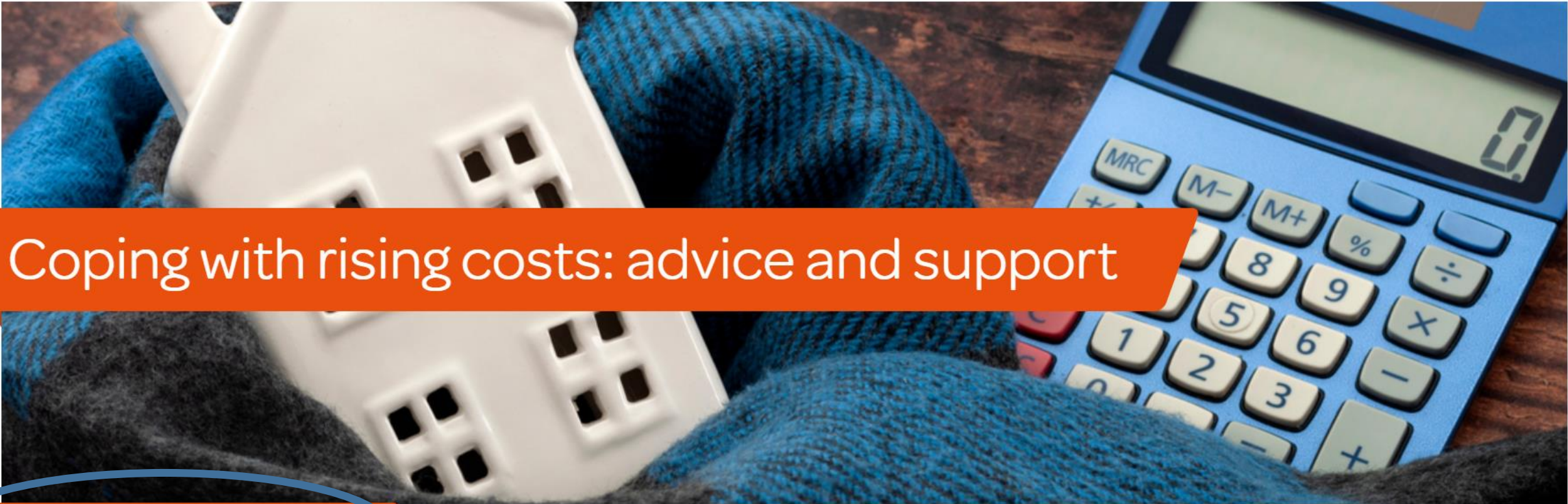
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Scotland Webinar

Welcome to the Kidney care in Scotland information webinar



11 March 2021

Hosted by Living Kidney Donation Scotland and Kidney Care UK



The Exceptional Gift



Kidney Care UK

Watch on YouTube

Kidney Care in Scotland Your Q&A's on living donation

Join our
information
webinar



The Exceptional Gift

Wednesday
16 June 2021
6.30 to 7.30pm



Kidney Care UK

Kidney care in a multicultural Scotland Information webinar

Thursday 2 September 2021
6.00 to 7.00pm



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Kidney Care UK



Online community

Our closed Facebook group puts you in touch with others affected by kidney disease

Young Adult Kidney Group (YAKG)

The Young Adult Kidney Group is a closed Facebook support group for kidney patients between 18 and 30 years o...

Let's talk about...

Social media appeals and healthcare professionals

There is an increasing use of social media by potential recipients and their families to highlight the need for a living donor. For some, this can be an effective means of communication with positive results. However, often the high level of enquiries does not translate into actual donation and the expectations of donors and recipients through this process need to be carefully managed. Taking early measures and having a clear local policy prepares everyone involved and should help manage the unplanned workload for transplant teams.

Key points for healthcare professionals

- If you are aware that a recipient or their family is planning a social media appeal, they must be advised to speak to the living donor team prior to the appeal. Direct recipients and donors to the information available here www.organdonation.nhs.uk/become-a-living-donor.
- Make it clear to potential recipients and families that all donors responding to appeals must approach the transplant teams via the usual channels. Recipients and families should not be involved in the selection process.
- Individual healthcare professionals must never be named on social media platforms. Generic contact details only to be provided.
- It is sometimes helpful to set a time limit to manage the process. For example, asking any potential donors to contact the team within a three-week period from the appeal. Agree a local strategy on reviewing potential donors e.g. group meetings, individual appointments, number and type of investigations for multiple donors.
- Agreement should be made with the transplant team on a communication strategy with recipients and their families. A clear understanding of the process of how potential donors are assessed in response to appeals will manage expectations.
- In all cases, use the opportunity to highlight non-directed altruistic donation and the benefits of living donation for those waiting for a kidney transplant.
- Any queries please contact the Clinical Lead for Living Donation at NHS Blood and Transplant via enquiries@nhsbt.nhs.uk.



Organ Donation and Transplantation 2030: Meeting the Need

A ten-year vision for organ donation and transplantation in the United Kingdom

In this strategy we will.....
“Explore all transplant and donation options at an early stage and in the context of other available treatment options to ensure that all suitable recipients have the opportunity of a transplant with the best outcome at the time they need it.”

Actions:

Ensure that the option of “transplant first” is considered for all suitable kidney recipients, especially pre-emptive transplantation.

Make it as easy as possible for people to give or receive a living donor kidney...by removing unwarranted barriers to donation.



Summary

- REACH pilot has provided insight into what is important to recipients and potential donors
- Preparing patients with a Transplant First approach is important for pre-emptive LDKT rates, but is resource intensive and needs to be a team effort
- Preparation needs to start as soon as it becomes clear RRT will be required in next two years if we are to increase pre-emptive/LDKT and tackle inequality of access
- Engaging with potential donors is very difficult for many patients but there are approaches that can help – again this needs to be a team effort