

Saying no to dialysis: information for carers

Introduction

For those caring for people with end stage renal disease it may be difficult to understand why their loved one might choose to withdraw from dialysis or not commence dialysis to treat their renal condition. Carers may not be happy with the decision taken and may try to get the patient to change their mind.

Why do people choose to withdraw from dialysis?

Some patients may feel exhausted by dialysis and that the treatment they are receiving is not improving their quality of life. They may feel very unwell when they go onto dialysis and they may not feel as though they have time to recover before the next dialysis session is required. Some patients have other illnesses other than their renal disease such as diabetes or heart complaints and these conditions may make the dialysis more difficult. For example some patients with heart disease may suffer from low blood pressure. This is made worse by dialysis. Others may experience pain when on dialysis.

Why people choose not to commence dialysis

Some patients may decide they do not want to start dialysis to treat their renal disease because of the complex treatment involved. In some instances their doctor may feel that dialysis will not be in their best interests particularly if they have other illnesses that may make the dialysis difficult to manage. Others may decide that they do not want to undertake a treatment that will require them visiting the hospital three times a week and enduring transport delays. These patients may feel they have lived a long life and particularly when older some will say enough is enough and decide they want to live out the remainder of their life without invasive treatment.

Helping patients decide where they wish to die

Whatever the reason for either withdrawing from or not commencing dialysis patients will require support from health care staff and from their loved ones. Hopefully they will have felt able to discuss their decision with staff and/or carers or family. Carers may also want to talk with the patients doctor or dialysis nurse either alone or with the patient.

Where possible it is usually best to have these meetings with everyone involved in the decision present. Once the decision to withdraw from dialysis has been made the patient will be given the option of returning home to die if this is their wish and carers feel that they will be able to manage this situation. Sometimes it is not possible for a patient to die at home for a number of reasons. There may be young children in the house and it may be decided they should not witness the death or a carer may be elderly themselves and in ill health and feel they cannot carry out the care that will be required. Others may feel this is not something they want to be involved in. Again talking with the patient and health care staff will help in deciding how best to manage the end of life. If a patient does go home to die the hospital staff will liaise with the GP and community staff to ensure that this request can be actioned and supported.

How long do people live without dialysis?

Once someone withdraws from dialysis they are likely to die within two weeks or longer if they still have some kidney function remaining. Some people may die in a matter of days and it is difficult to predict. Without dialysis treatment, fluid and toxins will build up in the body and the patient may become drowsy or breathless. The healthcare team either in the hospital or the community will provide medicines to treat any problems.

Further information

www.carersuk.org

www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Join the Renal Patient Support Group on Facebook:

www.facebook.com/groups/RPSGroup/?hc_location=stream



Dr Helen Noble, Lecturer, Queens University Belfast, Northern Ireland, UK. The information presented in this factsheet is accurate and current to the best of the author's knowledge. The author and publisher, however, make no guarantee as to, and assume no responsibility for, the correctness, sufficiency or completeness of such information or recommendation. The reader is advised to consult a doctor regarding all aspects of individual health care.

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