



Introduction

This submission responds to the Joint Oireachtas Committee on Disability Matters invitation to hear about the lived experience of people with disability. This submission addresses the lived experience of people living with kidney disease.

About the Irish Kidney Association

The Irish Kidney Association is a national charitable voluntary organisation founded in 1978. We are dedicated to meeting the needs of people living with and affected by end-stage kidney disease. With 25 branches the IKA is very active in the community and is led by a voluntary Board of patients and families.

About Kidney Disease

As of 31 December 2019, there were 2,196 people on dialysis and 2,625 people with a functioning kidney transplant.

When the kidneys stop working, most people develop conditions that affect the blood, bones, nerves, and skin. In addition to fatigue, loss of appetite, and leg cramps, some of the more common problems caused by kidney failure are itching, sleep problems, restless legs, weak bones, joint problems, and depression.

It is evident that the daily and long term illness burden of End Stage Kidney Disease (ESKD) for an individual is significant whatever their treatment (by dialysis or with a transplant). Given that a diagnosis of ESKD is often a person's first significant interaction with the health service, a typical patient will view their on-going health journey through that prism and will see issues such as 'weak bones and joint problems' as secondary even when they have a significant impact on their daily lives.

This perception is reinforced by the fact that in treating a kidney patient for such issues their kidney team will always be central to any decisions made. For a patient on dialysis any new medication has to be able to 'work' with dialysis and not be washed out of the blood stream during treatment. For a transplant recipient any new medications would have to work alongside their **immunosuppression** and steroids. Equally, when a transplant recipient requires surgery, it is always done with very close consultation with their kidney team because of their life-long need for immunosuppression.



As a consequence, there is currently no clear pathway for kidney patients to access disability supports as they tend to be viewed as being in a 'grey' area in relation to a variety of supports for secondary health issues that they can develop as a consequence of their end stage kidney disease.

'Hidden' disabilities for people on dialysis:

- **Fatigue**

Fatigue is a very common on-going issue for people on dialysis to the point that continuing with a job or a place in education can be challenging if not impossible and general daily activity may also have to be limited.

- **Physical Ability**

Whether a person is on **peritoneal dialysis** (PD) or **haemodialysis** (HD) their ability to carry out physical activity is compromised. Medical advice is that PD patients are advised against lifting anything of significant weight as they have a **catheter** fitted in their stomach. Equally, HD patients are restricted in their activity as they have to protect their **fistula** which is normally in one of their arms.

- **Bone Density**

Over time, dialysis has an impact on bone density with patients developing Renal Bone Disease and / or osteoporosis. This obviously impacts on all lifestyle choices and activities.

- **Treatment time**

A person on dialysis has to factor in significant treatment time into their daily programmes. Approximately 88% of people on dialysis are on haemodialysis and they attend a hospital/dialysis unit three times a week every week (156 times a year). A typical treatment time is 3-4 hours. With the limited availability of dialysis sessions a person starting haemodialysis generally has to fit their life around the shift that is available rather than fitting dialysis into their life. This obviously impacts on everything from availability / ability to work, child-minding, going on holidays and many more daily activities we tend to take for granted.

Additionally the lack of integrated care services may mean multiple visits to many different care professionals adding to the treatment burden.



- **Diet**

People with ESKD must follow a prescribed diet of restricted food and drink. This can significantly impact their activities of daily living. It can also affect their ability to socialise in restaurants and pubs. With the predominance of alcohol in Irish social life, this can be very isolating

- **Mental Health**

The mental health impact of end stage kidney disease is significant. It can rob a person of their sense of identity as it robs them of a level of their independence.

End stage kidney disease is often a silent disease with the individual only finding out late in the day that they require immediate intervention through dialysis treatment or a kidney transplant. This can lead to an individual losing confidence in their own bodies.

Depression can be extremely disabling when it comes to carrying out normal daily functions and thus have a dramatic impact on their ability to be a fully functional member of society.

The in-centre dialysis experience can be very different, depending on location. For example, Tallaght hospital has recently opened a new dialysis unit with increased capacity whilst the dialysis unit in Sligo remains overcrowded with patients waiting in a narrow corridor where trolleys with deceased people are wheeled by them. This is very distressing for patients.

- **Financial Cost**

A person on dialysis will be on regular medication to a point where, without a medical card, (there is no automatic entitlement to a medical card) they may well hit the monthly €124 charge. Equally, as time goes on, a person on dialysis is going to require in-patient treatment which also incurs cost. These are some of the actual costs, one must also consider the potential lost opportunities to earn income.

An extremely common feature of the illness burden for people on dialysis is constantly feeling cold. This leads to significant expenditure on heating at home and without a medical card this can be challenging to cover from what is already a likely compromised income.



Transplant Recipients:

Transplantation, when appropriate, is the gold medal standard of treatment for people living with end stage kidney disease as there are better clinical outcomes and reduced costs of treatment for the Health Care system. Not only does it improve a person's life expectancy, it has a significantly positive impact on their quality of life. However, it must be understood that a kidney transplant is not a cure, it is still a treatment and as such there are going to be consequences to manage.

- **Medication**

Immunosuppression is a fantastic development that has allowed organ transplantation to happen. However, it comes at a price. Transplant recipients are at a significantly increased risk of problems such as skin cancers because of their medication. Prevention and treatment comes at a cost. Recipients should be using specific sunscreen 365 days a year and also need to attend regular skin care clinics. The risk impacts on their choice of work / play activities. Whilst the cost of high tech medications is covered by the State, without a medical card a transplant recipient will have significant medication costs throughout the year.

- **Mental Health**

A kidney transplant is a gift of life, it is viewed as a reason to celebrate but it can also be challenging to handle the mental impact whilst society expects the person to be 'normal' again.

It is a sudden change in identity in the case of deceased donation as the timing cannot be planned. There's the bittersweet thought that there is a family out there grieving whilst the patient, and their family, are 'celebrating.' Survivor's guilt can be an issue.

Typically a kidney transplant is celebrated as a step towards 'freedom' from the significant burden of dialysis treatments but it can also be a scary new reality as the person adapts to a 'new life' without the safety net of the three times a week in the dialysis unit. A compromised immune system and the understanding that the organ may reject / fail are very real also.

These changes can be very disabling as a person strives to 'return to normality.' The fear of losing a transplant can be significant and result in recipients engaging fully with life.



Social welfare interaction with work

Many ESKD patients wish to return to full or part time work. Unfortunately the loss of key benefits such as the medical card or disability benefit can mean the person is worse off financially by returning to work¹.

Family and the bigger picture

Organ failure impacts everyone in a household. Whether it is the individual's compromised ability to work or carry out their normal share of domestic duties, the uncertainty around their health and life expectancy or simply adapting the meal routine to account for the kidney diet it is there every day. This is all without addressing the treatment burden of the disease.

The family also are often left to carry the burden of the secondary health issues that can develop as a consequence of end stage kidney disease. The 'system' currently can struggle to see beyond the kidney failure because of its primacy in all care and rehabilitation plans.

Kidney failure is often left in that grey area of whether it is a 'real' disability compared to the 'traditional' physical and sensory disabilities. Transplant recipients in particular often do not want the moniker of being 'disabled.' Transplantation is generally 'sold' as being the gift of life so there can be a sense of responsibility to the donor to live an active and 'normal' life and thereby ignore the secondary disabilities that can accompany end stage kidney disease. There is a need for a societal shift to remove the stigma associated with having a disability before we will see all those who would benefit from outside supports stepping forward to ask for help.

¹ Make Work pay for people with disabilities at <https://static.rasset.ie/documents/news/2017-03-04-makeworkpay-report.pdf>



Impact of COVID

People with ESKD are in the highly vulnerable group of people with an increased rate of mortality. Initial medical advice was to cocoon with consequent impacts on many people's mental health². For people attending hospitals, there was fear and anxiety about the risks of attending hospitals. Also, in the initial stages, people were not allowed to eat during dialysis which caused severe issues for patients, particularly for diabetic patients. It should be noted that malnourishment can be a feature of ESKD.

Transport arrangements were changed as people were no longer able to share transport. In the initial stages there were problems with patients driving themselves receiving a mileage fee and we still note delays of payments in some instances. For people on low incomes, this can cause significant stress.

For people on home dialysis, who receive regular deliveries of supplies which can be on a pallet, there were problems when drivers were no longer allowed to enter their houses. A new protocol has now been put in place to allow drivers to enter the patient's house where the patient's own family cannot move the equipment. However, the Clinician must complete an assessment to enable this change, the patient cannot request this which reduces their agency and autonomy.

Transplant Operations ceased for a period thus leading to longer waiting lists,

Conclusion

The impact of end stage kidney disease (EKSD) is considerable. Please contact us if you require any further information.

Contact Details

Email Info@ika.ie

Facebook – www.facebook.com/IrishKidneyAssociation

Twitter – www.twitter.com/IrishKidneyAs

Instagram – www.instagram.com/IrishKidneyA

LinkedIn – www.linkedin.com/company/IrishKidneyAssociation

Website – www.ika.ie

² For example, of one persons lived experience see Page 19 "Life in lock down" at https://ika.ie/wp-content/uploads/2020/10/IKA_SUPPORT_AUTUMN_2020_WEB.pdf