



# Dietetic Challenges Post Kidney Transplant in Children



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Kidney transplant is not a cure for chronic kidney disease (CKD), but it is currently the best treatment option available for children with end-stage kidney disease. Metabolic syndrome, which has been described as the presence of overweight or obesity and at least two of four additional cardiovascular risk factors (e.g. hypertension, elevated fasting triglycerides, reduced HDL levels, diabetes/impaired glucose tolerance),<sup>1</sup> is known to affect children at all stages of CKD, including those who have received a kidney transplant.<sup>1</sup> Children with certain underlying kidney diseases – for example, nephropathic cystinosis and cystic kidney diseases – are known to be at greater risk of developing new onset diabetes after a kidney transplant.<sup>1</sup> Whilst immunosuppressive medications are a known risk factor for dyslipidaemia post kidney transplant,<sup>2,3</sup> therapeutic lifestyle changes such as dietary counselling, attention to a healthy diet and adequate physical activity<sup>4,5</sup> are recommended in its management. These interventions are also recommended in the management of hypertension and excessive weight gain/obesity<sup>6</sup> following a kidney transplant.

## Background

There is a high prevalence of overweight and obesity in children who have received a kidney transplant.<sup>7,11</sup> One UK study showed that the proportion of children classified as overweight or obese increased from 31.4% pre transplant to 52.8% four years post kidney transplant.<sup>10</sup> Weight gains appear to occur early post kidney transplant and persist for years after.<sup>8,10</sup> Several factors may contribute to post kidney transplant weight gain, including improved taste sensation following resolution of uraemia, liberalisation of diet, improved appetite, as well as appetite stimulation in those receiving corticosteroids.<sup>6,12</sup> However, positive effects on growth and body-mass index (BMI) have been shown following recent advances in steroid-free immunosuppression post kidney transplant.<sup>13</sup> More universal use of steroid sparing treatments following a kidney transplant in the UK may lead to reductions in the proportion of children with obesity.

There is currently no evidence to suggest that children who have received a kidney transplant have energy requirements different to those for healthy children.<sup>6</sup> Whilst the percentage of underweight children post kidney transplant is much lower than those who are overweight or obese,<sup>9,11,14</sup> ongoing dietetic input and management is also required in these children to ensure appropriate weight gain. The proportion of children that are underweight post kidney transplant varies in the literature. For example, the study by Winnicki *et al.*<sup>14</sup> reported that 6% of

children were underweight post renal transplant. In comparison, the study by Bonthuis *et al.*<sup>9</sup> reported a prevalence of 1.3%. In paediatric renal transplant patients, a younger age has been shown to be associated with a significantly higher risk of being underweight.<sup>9</sup>

## Nutrition support

It is known that the provision of adequate nutrition post kidney transplant is important to help promote anabolism and wound healing.<sup>6</sup> Children with delayed normalisation of kidney function following a kidney transplant will often need to continue with some dietary restrictions until kidney function normalises and will therefore require tailored dietetic advice to support with this.

In addition, due to the immunosuppressive medication required following a kidney transplant, education on food hygiene and the avoidance of foods which may have a high risk of food borne infection or food poisoning has been suggested.<sup>6</sup>

Infants and children with CKD may require exclusive or supplemental enteral tube feeding if they are unable to meet their nutritional requirements orally.<sup>6,15</sup> It has been shown that transition from enteral tube feeding to oral diet can occur within weeks post kidney transplant in the majority of children.<sup>16,17,18</sup> However, if early feeding experiences were not positive, oral feeding issues may remain post kidney transplant.<sup>19</sup> Regular dietetic monitoring during this transitional phase is important to help ensure that nutrition is optimised whilst meeting fluid targets.

## Dietetic workforce

The Paediatric Renal Nutrition Taskforce, which comprises paediatric nephrologists and paediatric renal dietitians from nine countries across Europe and North America, recommend dietetic contact at each visit for children post kidney transplant with obesity and metabolic syndrome.<sup>1</sup> Recent data from the UK Renal Registry showed that 1031 children <16 years of age had severe chronic kidney disease (estimated glomerular filtration rate <30 mL/min/1.73 m<sup>2</sup>), of which -64% had a functioning kidney transplant.<sup>20</sup> The demands on the existing paediatric renal dietetic workforce are high and have been shown to be increasing.<sup>21</sup> For example, the suggested frequency of dietetic contacts, based on expert opinion for infants with stages 3b to 5, is monthly and for infants and children with CKD stage 5D the suggested frequency is also monthly.<sup>22</sup> More frequent dietetic input may be required in infants and children where there are concerns with weight gain or growth. However, the most recent data has shown that no UK centre has the recommended staffing levels of paediatric renal dietitians, with a mean deficit of 55.2% (range 20.2% to 86.8%),<sup>21</sup> which is likely to be having a negative impact on patient care across all stages of CKD.

## Understanding current services & resources

### Parent/carer feedback

It is important to consider the views of parents/carers in developing national guidance for dietetic input following a kidney transplant and when supporting additional funding for dietetic posts in this area. In March 2023, we completed an electronic survey with parents/carers (n=21) containing questions that focused on their views on the frequency of dietetic input, any perceived concerns with their child's nutrition and/or weight, as well as feedback on the paediatric renal dietetic service post kidney transplant. Ninety per cent of parents/carers would like the initial dietetic advice post kidney transplant to be given face-to-face. Overall, 52% and 24% would like this information in a leaflet and video format respectively.

Amongst the information parents/carers would like to receive included frequent

reminders on foods and drinks to be avoided, updates on research in post kidney transplant nutrition and support with health eating. Thirty per cent of parents/carers reported concerns with their child's weight, 18% of which were concerned with large weight gain, whilst the remaining 12% were concerned that their child was underweight. The majority of parents/carers (95%) would like regular follow up appointments with the paediatric renal dietitians following their child's kidney transplant, of which 25% would prefer every 3 months, 35% every 6 months and 25% would prefer an annual review.

### Healthcare professional feedback

In the UK, there are 13 paediatric renal centres, however there is limited published data on the paediatric renal dietetic services for children who have received a kidney transplant in the UK. Between February to March 2023, we completed an electronic survey to identify the current paediatric renal dietetic services for this patient group in the UK, receiving responses from a dietitian in each of the UK paediatric renal centres. Results of the survey showed that, at present, there is a lack of protocols on early post-operative nutrition following a kidney transplant.

Concerns were noted by paediatric renal dietitians with regards to patient information leaflets, with almost a third reporting that improvements were required in the paediatric renal dietetic education resources for this patient group. Whilst all paediatric renal dietetic teams offer healthy eating advice post kidney transplant, due to capacity issues, only 31% of paediatric renal dietitians can offer regular follow up appointments. The main dietetic concerns reported by the paediatric renal dietitians for children post kidney transplant were large weight gain following a kidney transplant (92%), weaning off of enteral tube feeds (25%) and adherence to healthy eating advice (25%). Eighty-two per cent of those surveyed would like a paediatric renal dietitian allocated to this patient group. From responses received, at present only one UK paediatric renal centre had a dietitian whose role included attendance at their transplant clinics.

When we asked consultant paediatric transplant nephrologists (n=8) from the UK paediatric renal centres how regularly follow

up appointments with dietitians are required in this patient group, the main responses were 3-monthly (37.5%) or review on request (37.5%). It was acknowledged that dietetic input would need to be more frequent for selected groups, for example, children receiving enteral feeds. In comparison to 70% of dietitians who felt that this patient group could be managed by community dietetic teams, the majority (-63%) of the consultant paediatric transplant nephrologists disagreed. Amongst the main reasons given by the paediatric transplant nephrologists were lack of capacity and understanding of issues involved; lack of communication with the paediatric renal MDT and relationships already established with the acute paediatric renal dietitians. Fifty per cent of the consultant nephrologists noted a preference for paediatric renal dietetic presence at each paediatric renal transplant clinic.

## In summary

Overall, the above surveys identified a need to improve the current paediatric dietetic services to paediatric kidney transplant patients in the UK. This includes the need for improvement in resources, including a paediatric dietitian allocated to this patient group, contact with a dietitian at each clinic visit for specific groups of children and improvements in nutrition guidances and dietetic education resources to better support children who have received a kidney transplant. At the time of these surveys there were no paediatric specific video resources, developed by dietitians, available to parents/carers in the UK on healthy eating after a kidney transplant. In July this year, following the results of these surveys, we worked with VitaFlo to develop an information video on healthy eating post kidney transplant. This resource is now available on [www.myrenalnutrition.com](http://www.myrenalnutrition.com), a website produced by VitaFlo (International) Ltd for parents/carers, dietitians and members of the paediatric renal transplant teams.<sup>23</sup>

The views of parents/carers are essential when supporting additional funding for dietetic posts in this area. We have shown that the majority of parents/carers surveyed would like regular follow up appointments with the paediatric renal dietitians following their child's kidney transplant, preferably every 3-6 months (60%).

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