UniversitätsKlinikum Heidelberg

# Transition to Adult Healthcare: Current Discussions

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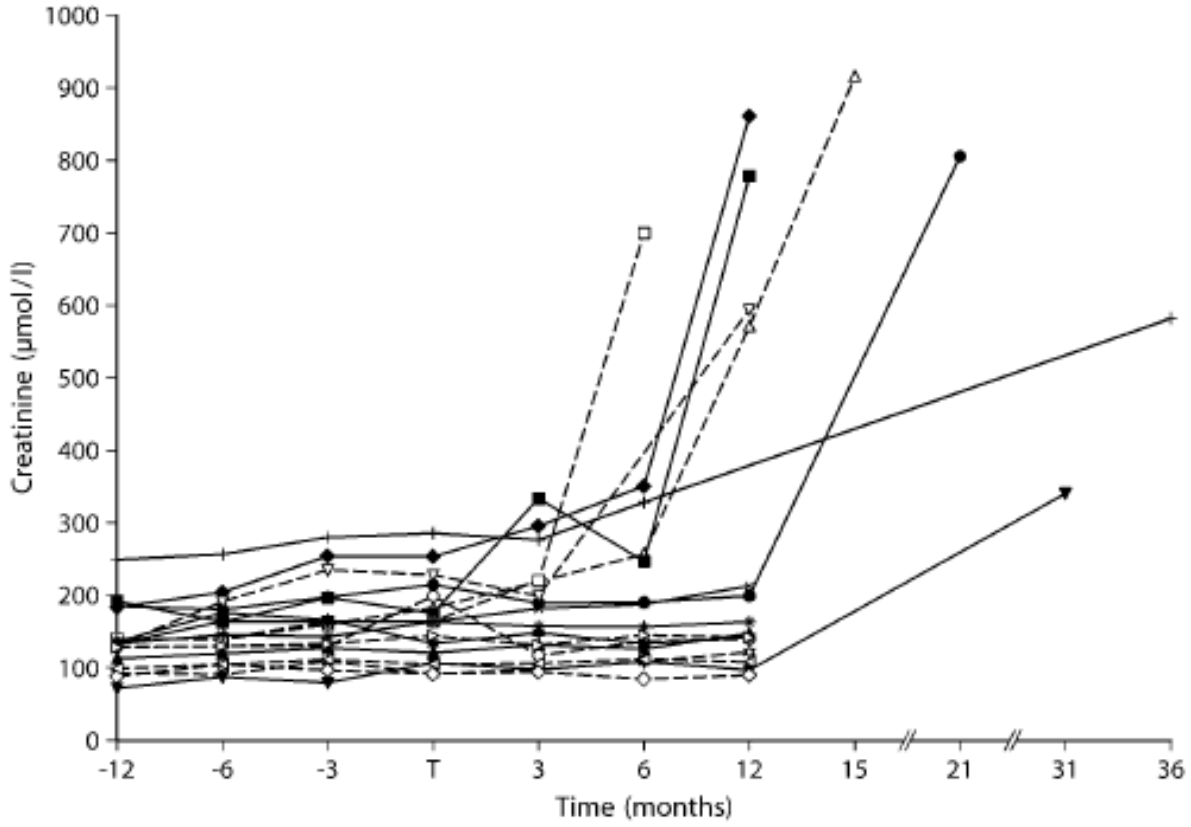
Creatinine (µmol/l)
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700
600
500
400
300
200
100
0
-12
-6
-3
T
3
6
12
15
21
31
36
Time (months)

Watson 2000

**Transition**

*“ is the purposeful, planned movement of adolescent and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems“ (Blum et al. 1993)*

= Process

**Transfer**

= the single event during the process of transition when the patient actually changes the caregiving institution

1) **Heidelberg pediatric renal unit: psychosocial transition/ transfer recommendations**

2) **German transition discussion**

3) **Issues of the international debate**

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

Basic principle: the transfer to the adult unit is a very important event in the biography of a chronically diseased young person. It needs a thorough preparation.

General guidelines

1) The actual transfer to the adult unit should not happen before the age of 18 years since at this age the necessary criteria are usually not met yet. Most patients are transfered in their early twenties.

2) The school education should be completed.

3) The vocational education should be completed or, at least, be on a stable course.

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

4) The degree of the patient‘s autonomy and self-advocacy should allow a self-reliant dialogue with the doctor. Therefore, it is important that the pediatric nephrologist practices this with the patient rather than only addressing the parents.

5) The general situation of the patient should be medically and psychologically stable.

6) Prior to transfer, the patient should have the opportunity to participate with the national transition support project „Endlich Erwachsen“ (= finally grown-up).


Datei Bearbeiten Ansicht Favoriten Extras ?
startseite | KfH - endlich erwachsen
Seite Extras
TRANSFERPROGRAMM
endlich erwachsen
Start | Kontakt | KfH | Sitemap
A- A A+
Suche:
Informativ
Interaktiv
Community
Job & Schule
Auch mit einer chronischen Nierenerkrankung gibt es verschiedene Möglichkeiten, die Schule zu besuchen oder einen Beruf zu erlernen. Unterstützung gibt es für Betroffene bei mehreren Anlaufstellen. ...
Inhalt
Die Erfolge der Nierenersatztherapie bei Kindern (Nierentransplantation, Hämodialyse und Peritonealdialyse) ermöglichen es heute, erwachsen zu werden und Jahrzehnte zu überleben. ...
Das Programm
Das Transferprogramm „endlich erwachsen" wurde im Jahr 2003 eingeführt, um chronisch nierenkranken Jugendlichen den Übergang aus dem vertrauten Umfeld der Kinderdialyse in den Bereich der Erwachsenenbetreuung und damit ihr Leben und ihre besonderen Probleme in der Phase des Erwachsenwerdens zu erleichtern. ...
Downloads
Hier kannst Du alles rund ums Thema endlich erwachsen downloaden. ...
Transplantation
Bei der Nierentransplantation wird eine Spenderniere auf einen chronisch nierenkranken Menschen übertragen, die alle Funktionen einer gesunden Niere übernimmt. ...
Login:
Benutzername:
Passwort:
Neu anmelden
Passwort vergessen?
Erfahrungsbericht
Benny, 21
Ich wurde am 6.September 1988 in Aschaffenburg geboren. ...
Schirmherrschaft
Hockey-Nationalspieler Moritz Fürste ist seit 2006 Schirmherr von endlich erwachsen. ...
Auf einen Klick
Programm
Team
Forum
Übersicht Kinderzentren (PDF)
Internet
100%

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

Special cases

An extended pediatric care can be necessary in the following cases:

- Mental retardation of the patient and unclear longterm placement
- Living with foster parents or in a children‘s home with unclear future housing and living situation

Transfer is a process = transition

- Prepare the transfer with enough time and in consensus with the patient family
- promoting the self-reliance and self-advocacy of the patient
- Final counseling with the unit psychologist before actually leaving the unit

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

Preparing the patient family

- Individualized and specialized medical and nursing care in the pediatric unit
- Individualized psychosocial need assessment and family support
- Specialized transplant nurse at the outpatient‘s to counsel family and especially adolescents and young adults
- Individualized training in self-management skills during summer camps

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

Preparing the patient family

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- Individualized psychosocial need assessment and family support
- Specialized transplant nurse at the outpatient‘s to counsel family and especially adolescents and young adults
- Individualized training in self-management skills during summer camps
- Encouraging networking and peer support, e.g. by carrying out summer camps

# 1) Heidelberg pediatric renal unit: psychosocial transition/transfer recommendations

What do we still miss in Heidelberg?

- Flexibility of transfer timing also for dialysis patients
- Special care solutions for hemodialysis patients who live far away
- Joint clinics adult/pediatric
- Regular and institutionalized collaboration and cooperation between pediatric and adult unit(s)
- More nursing and psychosocial staff to design and carry out patient and family training at the pediatric unit
- Purposeful and planned continuation of the transition process after transfer
- Psychosocial staff at the adult units

# 2) German transition discussion

• Advisory Council for Health Dept. 2009:

unlike in UK, US, AUS in Germany no coordinated national programs for chronically ill adolescents, only local initiatives. Pilot projects incl. evaluation are needed!

• Transition Conference of the German Medical Association, March 2011: further research is needed to find adequate transitional care solutions for the different disease groups. But liberalization of transfer timing could be realized immediately!

• Special edition of „Der Nephrologe“ on „Transition nephrology“

# 3) Issues of the international debate

- „Growing up and moving on: Transition from pediatric to adult care“, review, McDonagh 2005

- „Readiness for Transition to Adult Care: Pediatric Kidney Transplant Patients“, Best Evidence Statement, Cincinnati Children‘s, 2008

- „ Adolescent Transition to Adult Care in Solid Organ Transplantation“, Consensus conference report, Bell et al. 2008

- „Building Consensus on Transition of Transplant Patients from Paediatric to Adult Healthcare“, Report of UK conference, Webb et al. 2010

- „Helping Adolescents and Young Adults with Endstage Renal Failure“, British Association for Pediatric Nephrology, Renal Association, 2009

# 3) Issues of the international debate

- „Transition from pediatric to adult renal services: a consensus statement“, International Pediatric Nephrology Association, International Society for Nephrology, coordination: Alan Watson, in progress

# 3) Issues of the international debate

**The aims of transition are**

1. To provide high quality, co-ordinated, uninterrupted healthcare which is patient-centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive

2. To promote skills in communication, decision-making, assertiveness, self-care, self-determination and self-advocacy

3. To enhance sense of control and interdependence in healthcare

4. To maximize life-long functioning and potential

5. To support the parent(s)/guardian of the young person during transition and in particular to enhance their advocacy skills

**McDonagh 2005**

# 3) Issues of the international debate

**Timing of transition and transfer, depending on**

- Chronological age
- Maturity: physical and cognitive
- Current medical status
- Adherence to therapy
- Independence in healthcare
- Preparation of young person and family
- Readiness of the young person
- Readiness of the parent/guardian
- Availability of an appropriate adult specialist

**McDonagh 2005**

# 3) Issues of the international debate

## Key elements of transitional care:

An orientation that is future focussed, proactive and flexible
An early start!
A key worker identified for each individual patient
A written transition policy agreed by all members of the multidisciplinary team and target adult services
A flexible policy on timing of events with anticipation of change
An approach which fosters personal and medical independence and creative problem solving
A preparation period for patient and parent
An education programme for patient and parent which addresses medical, psychosocial and educational/vocational aspects of care
A written individualized health care transition plan by age 14 created with the young person, their family with regular review and update
Liaison personnel in both paediatric and adult teams
A network of relevant local agencies and target adult services
Administrative support including provision of medical summary that is portable and accessible
A training programme for paediatric and adult team members
Primary and preventive care involvement and provision
Affordable continuous health insurance coverage (if applicable) for all young people with special health care needs throughout adolescence and adulthood

**McDonagh 2005**

# Personal Commentary:

- International consensus finding is very helpful; implementation of transition programs highly depends on local and national health care circumstances.
- Transition programs need additional psychosocial resources!
- Inclusion of patient‘s and parent‘s viewpoints, wishes, needs; use of qualitative methodology

# Thank you!