# EACH Library Literature Search

# Title: Transition

Requested by: Lizzie Chambers  Completed by: Sue Langley

Date requested: 29th July 2022  Date sent: 5th August 2022

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1. **Adult healthcare is associated with more emergency healthcare for young people with life-limiting conditions.**
   **Item Type:** Journal Article
   **Authors:** Jarvis, S.;Flemming, K.;Richardson, G. and Fraser, L.
   **Publication Date:** 2022
   **Journal:** Pediatric Research (pagination), pp. 2022
   **Abstract:** Background: Children with life-limiting conditions receive specialist paediatric care in childhood, but transition to adult care during adolescence. There are concerns about transition, including a lack of continuity in care and that it may lead to increases in emergency hospital visits.

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2. **The Transition to Adulthood for Youth Living with Rare Diseases**
   **Item Type:** Journal Article
   **Authors:** Sandquist, Melanie;Davenport, TjaMeika;Monaco, Jana and Lyon, Maureen E.
   **Publication Date:** 2022
   **Journal:** Children 9(5), pp. 710-N.PAG
   **Abstract:** More children with rare diseases survive into adulthood. The transition period to adult healthcare presents many challenges for pediatric rare diseases. Few adolescents or their families receive any transitional support for the transition to adult healthcare or for their maturing psychosocial needs. Understanding the challenges in the transition process is critical to ensure that interventions designed to improve the transition are holistic and meet the needs of the youth and their families. Few transition programs are in place to meet the needs of those youth with rare diseases who cannot participate in medical decision making or who live independently because of severe disabilities and comorbidities. We searched the literature on preparation and outcomes for youth living with rare diseases in PubMed, CINAHL, and PsychInfo, excluding publications before 2010. The results revealed seven studies specific to rare diseases, special needs, or chronic conditions. Next, we discussed transition with experts in the field, GotTransition.org, and citation chaining, yielding a total of 14 sources. The barriers and challenges to transition were identified. Articles discussing solutions and interventions for transition in medically complex children were categorized care coordination or transition readiness. A large portion of children with rare disease are underserved and experience health disparities in transition.

**DOI:** https://libkey.io/10.3390/children9050710

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3. **Young adults with life-limiting or life-threatening conditions: sexuality and relationships support.**
**Item Type:** Journal Article
**Authors:** Earle, Sarah and Blackburn, Madeleine
**Publication Date:** Jun ,2021
**Journal:** BMJ Supportive & Palliative Care 11(2), pp. 163-169
**Abstract:** OBJECTIVE: The research project addressed the need to support young adults with issues relating to sexuality and relationships though the development of guidance and standards for practice. METHODS: An action research project underpinned by an interpretivist qualitative framework. Participants were recruited to the project via three hospices in the UK. Data from four focus groups were analysed thematically using a process of constant comparison. RESULTS: Sixteen young adults with life-limiting or life-threatening conditions aged 21-33 years participated in the study. Three significant themes were identified: sexuality and the transition to adulthood, recognising the significance of sex and relationships, and realising sexual rights. CONCLUSION: Sexuality and relationships play an important role in the transition to adulthood for people with life-limiting or life-threatening conditions living in the UK. While young adults with these conditions may have considerable support needs, it is important to balance this with the freedom to exercise choice and to make independent decisions. Sex negativity can have an adverse impact on the experiences of young adults and creates barriers. Improved ongoing access to sex education and the provision of enabling environments that afford privacy and safety are important to support young adults with sexuality and relationships. Copyright © Author(s) (or their employer(s)) 2021. No commercial re-use. See rights and permissions. Published by BMJ.

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4. **Troubling norms? Adults and teenagers with a life-limiting impairment in Denmark and England talk about their lives, support and future plans.**
**Item Type:** Journal Article
**Authors:** Hoskin, J.
**Publication Date:** 2021
**Journal:** European Journal of Special Needs Education 36(3), pp. 329-343
**Abstract:** There are an increasing number of young people with a range of life-limiting impairments in our schools, colleges, universities and communities. One of these impairments is Duchenne Muscular Dystrophy (DMD), a rare, life-limiting genetic muscle-wasting impairment that affects predominantly males. Twenty years ago, most people with DMD did not live past the age of twenty years, but now due to a range of treatments they are living longer. However, education and social care services are often yet to catch up with this improved prognosis. The aim of this paper is to compare the findings from structured conversations with members of the DMD community in Denmark and England. Historically, adults in Denmark have reported a good quality of life with an optimal health care programme and generous social care, whereas adults with DMD in England have reported poor transition to adulthood planning leading to social isolation as an adult. Findings identified three key themes: the existence of normative goals; expertise from lived experience, and the meaning of independence for someone with a complex impairment. These themes are further discussed through the lens of 'post-human thinking', and implications for practice are explored.

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5. **Transition of children with life-limiting conditions to adult care and healthcare use: a systematic review.**
**Item Type:** Journal Article
**Authors:** Jarvis, Stuart W.;Roberts, Daniel;Flemming, Kate;Richardson, Gerry and Fraser, Lorna K.
**Publication Date:** 2021
**Journal:** Pediatric Research 90(6), pp. 1120-1131
**Abstract:** BACKGROUND: Improved survival has led to increasing numbers of children with life-limiting conditions transitioning to adult healthcare services. There are concerns that transition may lead to a reduction in care quality and increases in emergency care. This review explores evidence for differences in health or social care use post- versus pre-transition to adult services. METHODS: MEDLINE, EMBASE, CINAHL, PsychINFO and Social Science Citation Index were searched. Studies published in English since 1990 including individuals with any life-limiting condition post- and pre-transition and reporting a health or social care use outcome were included. Data were extracted and quality assessed by one reviewer with 30% checked by an independent reviewer. RESULTS: Nineteen papers (18 studies) met the inclusion criteria. There was evidence for both increases and decreases (post- versus pre-transition) in outpatient attendance, inpatient admissions, inpatient bed days and health service costs; for increases in Emergency Department visits and for decreases in individuals receiving physiotherapy. CONCLUSIONS: Evidence for changes in healthcare use post- versus pre-transition is mixed and conflicting, although there is evidence for an increase in Emergency Department visits and a reduction in access to physiotherapy. More high-quality research is needed to better link changes in care to the transition. IMPACT: Evidence for changes in healthcare use associated with transition to adult services is conflicting. Emergency Department visits increase and access to physiotherapy decreases at transition. There are marked differences between care patterns in the United States and Canada. Copyright © 2021. The Author(s).

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6. **Transition from children's to adult services for adolescents/young adults with life-limiting conditions: Developing realist programme theory through an international comparison.**
**Item Type:** Journal Article
**Authors:** Kerr, H.;Widger, K.;CullenDean, G.;Price, P. J. and O'Halloran, P.
**Publication Date:** 2021
**Journal:** Palliative Care and Social Practice.Conference: Public Health Research in Palliative Care: Towards Solutions for Global Challenges.Online 15, pp. 3-4
**Abstract:** Background and rationale: Managing the transition of adolescents/young adults with life-limiting conditions from children's to adult services has become a global health and social care issue. Suboptimal transitions from children's to adult services can lead to measurable adverse outcomes. Interventions related to a successful transition to adult services are emerging, but there is little theory to guide service developments aimed at improving transition. The Transition to Adult Services for Young Adults with Life limiting conditions (TAYSL study) involved the development of the TASYL Transition Theory based on a research study in the context of the island of Ireland, which describes 8 interventions, which can help prepare services and adolescents/ young adults with life-limiting conditions for a successful transition to adult services.

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7. **Challenges in Transition From Childhood to Adulthood Care in Rare Metabolic Diseases: Results From the First Multi-Center European Survey.**
**Item Type:** Journal Article
**Authors:** Stepien, Karolina M.;Kiec-Wilk, Beata;Lampe, Christina;Tangeraas, Trine;Cefalo, Graziella;Belmatoug, Nadia;Francisco, Rita;Del Toro, Mireia;Wagner, Leona;Lauridsen, Anne-

Grethe;Sestini, Sylvia;Weinhold, Nathalie;Hahn, Andreas;Montanari, Chiara;Rovelli, Valentina;Bellettato, Cinzia M.;Paneghetti, Laura;van Lingen, Corine and Scarpa, Maurizio
**Publication Date:** 2021
**Journal:** Frontiers in Medicine 8, pp. 652358
**Abstract:** Inherited Metabolic Diseases (IMDs) are rare diseases caused by genetic defects in biochemical pathways. Earlier diagnosis and advances in treatment have improved the life expectancy of IMD patients over the last decades, with the majority of patients now surviving beyond the age of 20. This has created a new challenge: as they grow up, the care of IMD patients' needs to be transferred from metabolic pediatricians to metabolic physicians specialized in treating adults, through a process called "transition." The purpose of this study was to assess how this transition is managed in Europe: a survey was sent to all 77 centers of the European Reference Network for Hereditary Metabolic Disorders (MetabERN) to collect information and to identify unmet needs regarding the transition process. Data was collected from 63/77 (81%) healthcare providers (HCPs) from 20 EU countries. Responders were mostly metabolic pediatricians; of these, only ~40% have received appropriate training in health issues of adolescent metabolic patients. In most centers (~67%) there is no designated transition coordinator. About 50% of centers provide a written individualized transition protocol, which is standardized in just ~20% of cases. In 77% of centers, pediatricians share a medical summary, transition letter and emergency plan with the adult team and the patient. According to our responders, 11% of patients remain under pediatric care throughout their life. The main challenges identified by HCPs in managing transition are lack of time and shortage of adult metabolic physician positions, while the implementations that are most required for a successful transition include: medical staff dedicated to transition, a transition coordinator, and specific metabolic training for adult physicians. Our study shows that the transition process of IMD patients in Europe is far from standardized and in most cases is inadequate or non-existent. A transition coordinator to facilitate collaboration between the pediatric and adult healthcare teams should be central to any transition program. Standardized operating procedures, together with adequate financial resources and specific training for adult physicians focused on IMDs are the key aspects that must be improved in the rare metabolic field to establish successful transition processes in Europe. Copyright © 2021 Stepien, Kiec-Wilk, Lampe, Tangeraas, Cefalo, Belmatoug, Francisco, del Toro, Wagner, Lauridsen, Sestini, Weinhold, Hahn, Montanari, Rovelli, Bellettato, Paneghetti, van Lingen and Scarpa.

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8. **When a Child with Special Needs Becomes an Adult: The Journey of Transition and Hope Through the Uncertainty of Illness and Recovery...Dynamics of Critical Care Conference, September 28–30, 2020, Windsor, Ontario**
**Item Type:** Journal Article
**Authors:** Breen, Colleen and Blais-Nesbitt, Brenda
**Publication Date:** 2020
**Journal:** Canadian Journal of Critical Care Nursing 31(1), pp. 15
**Abstract:** Chronic illness impacts many children and families, creating health challenges that have a profound, life-long impact. Many children with chronic illness and disability are medically fragile, needing technology daily for survival and often experiencing life-threatening health crises that require intensive care. With advances in technology and therapies, children with special needs are living longer, often into adulthood. As a result, they must transition from pediatric to adult-based services, creating significant stressors for patients, parents, and caregivers. Parents of children and young adults with special needs have developed expertise in the needs of their children through years of advocacy in a healthcare system where they often feel marginalized. Based on her lived experience, a mother shares the story of her medically fragile daughter and her transition from pediatric to adult-based care, including admissions to both pediatric and adult critical care units. From her experiences and scholarly

evidence, this collaborative and interactive presentation by a parent and a critical care nurse highlights the impact of chronic illness and special needs on children, families and caregivers. The factors that influence adaptation to illness and coping will be reviewed. Important strategies for creating a seamless transition from pediatric to adult care are discussed. The importance of parent-caregiver collaboration and the impact on a meaningful transition in care is discussed. Themes in the journey of chronic illness and disability, including caregiver burnout and chronic sorrow, are outlined, along with the many ways that nurses can provide meaningful transitional support.

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9. **Transitioning adolescents on long term ventilation from paediatric to adult services: Parents' and carers' understanding and expectations of the transition process.**
**Item Type:** Journal Article
**Authors:** Brittenden, L.;Ahmed, M. I.;Hickey, H.;Mogford, L.;Elkington, B. and Jain, K.
**Publication Date:** 2020
**Journal:** European Respiratory Journal Conference, pp. European
**Abstract:** Background: The paediatric airway and Long Term Ventilation (LTV) service offers specialist care to approximately 50 patients requiring LTV of which 5 to 6 transition annually to the adult respiratory team. Transition to adult services for adolescents with complex and life limiting health conditions and their families can be experienced by them as a time of uncertainty and loss. Standardised models of transition may not be appropriate for children experiencing developmental, cognitive and emotional delay.

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10. **Tasks and interfaces in primary and specialized palliative care for Duchenne muscular dystrophy - A patients' perspective.**
**Item Type:** Journal Article
**Authors:** Janisch, Maria;Boehme, Kristin;Thiele, Simone;Bock, Annette;Kirschner, Janbernd;Schara, Ulrike;Walter, Maggie C.;Nolte-Buchholtz, Silke and von der Hagen, Maja
**Publication Date:** 2020
**Journal:** Neuromuscular Disorders 30(12), pp. 975-985
**Abstract:** In spite of the improvements in care and the emergence of disease-modifying treatments, Duchenne muscular dystrophy (DMD) remains a life-limiting disease of adolescence and (young) adulthood. Palliative care approaches and principles should be integrated from the point of diagnosis and implemented throughout the lifespan. A nationwide cross-sectional survey based on a mixed-method-design of qualitative and quantitative research approaches evaluated the structural implementation and perception of palliative care for DMD in Germany. Data analyses revealed that palliative care was predominantly provided at the primary care level by pediatricians, general practitioners and specialized multi-professional outpatient structures. The majority of patients did not utilize the scopes of specialized palliative structures. Simultaneously, insufficiently treated complex symptoms, emergent and elective hospitalizations and barriers in transitioning into adult care presented a considerable burden. A collaborative integrated model with a close cooperation of patients, families and care providers is proposed involving task areas and interfaces complementing primary and specialized palliative care (1) management of complex symptoms, (2) crisis support, (3) intermittent relief of the strain for caregivers, (4) coordination of care, (5) advance care planning and (6) end-of-life care. Specialized palliative care should be used as an "add-on" approach in time of need rather than as a prognosis or disease stage. Copyright © 2020 Elsevier B.V. All rights reserved.

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11. **A cross-sectional survey of services for young adults with life-limiting conditions making the transition from children's to adult services in Ireland.**
**Item Type:** Journal Article
**Authors:** Kerr, Helen; Price, Jayne and O'Halloran, Peter
**Publication Date:** Feb ,2020
**Journal:** Irish Journal of Medical Science 189(1), pp. 33-42
**Abstract:** BACKGROUND: Increasing numbers of young adults with life-limiting conditions are living into adulthood and consequently making the transition from children's to adult services. A poorly planned transition is associated with adverse outcomes such as non-adherence to treatment and loss to follow-up, together with negative social and emotional outcomes. However, there is little descriptive data on how organisations are currently managing transition. AIM: To obtain an overview of organisational approaches to transition on the island of Ireland, and to explore important organisational factors that may influence the effectiveness of the process. METHODS: A cross-sectional questionnaire survey. One of the four Health Services Executive areas in the Republic of Ireland and the whole of Northern Ireland. Participants were service providers in statutory and non-statutory organisations providing transition services to young adults with life-limiting conditions. RESULTS: The survey was distributed to 55 organisations. The overall response rate was 29/55 (53%). The approach to transition most commonly used focused on interagency communication and collaboration. Key factors in an effective transition were reported as: early commencement; effective communication between the young adult, their family, and services; the availability of appropriate adult services; and effective preparation through collaboration with the young adult and their family. However, implementation of these processes was inconsistent. CONCLUSIONS: The findings demonstrate that caring for young adults with life-limiting conditions presents a considerable challenge to organisations and that transition from children's to adult services is an important part of this challenge.

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12. **"Transition from children's to adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison"**
**Item Type:** Journal Article
**Authors:** Kerr, Helen; Widger, Kimberley; Cullen-Dean, Geraldine; Price, Jayne and O'Halloran, Peter
**Publication Date:** 2020
**Journal:** BMC Palliative Care 19(1), pp. 1-11
**Abstract:** Background: Managing transition of adolescents/young adults with life-limiting conditions from children's to adult services has become a global health and social care issue. Suboptimal transitions from children's to adult services can lead to measurable adverse outcomes. Interventions are emerging but there is little theory to guide service developments aimed at improving transition. The Transition to Adult Services for Young Adults with Life-limiting conditions (TAYSL study) included development of the TASYL Transition Theory, which describes eight interventions which can help prepare services and adolescents/young adults with life-limiting conditions for a successful transition. We aimed to assess the usefulness of the TASYL Transition Theory in a Canadian context to identify interventions, mechanisms and contextual factors associated with a successful transition from children's to adult services for adolescents/young adults; and to discover new theoretical elements that might modify the TASYL Theory. Methods: A cross-sectional survey focused on organisational approaches to transition was distributed to three organisations providing services to adolescents with life-limiting conditions in Toronto, Canada. This data was mapped to the TASYL Transition Theory to identify corresponding and new theoretical elements. Results: Invitations were sent to 411 potentially eligible health care professionals with 56 responses from across the three participating sites. The results validated three of the eight interventions: early start to the transition process; developing adolescent/young adult autonomy; and the role of parents/carers; with partial support for the remaining

five. One new intervention was identified: effective communication between healthcare professionals and the adolescent/young adult and their parents/carers. There was also support for contextual factors including those related to staff knowledge and attitudes, and a lack of time to provide transition services centred on the adolescent/young adult. Some mechanisms were supported, including the adolescent/young adult gaining confidence in relationships with service providers and in decision-making. Conclusions: The Transition Theory travelled well between Ireland and Toronto, indicating its potential to guide both service development and research in different contexts. Future research could include studies with adult service providers; qualitative work to further explicate mechanisms and contextual factors; and use the theory prospectively to develop and test new or modified interventions to improve transition.

**DOI:** https://libkey.io/10.1186/s12904-020-00620-2

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13. **Supporting transition through developing self-determination: Lessons from UK hospice a transition project.**
**Item Type:** Journal Article
**Authors:** Papworth, A.;Taylor, J. and Beresford, B.
**Publication Date:** 2020
**Journal:** Developmental Medicine and Child Neurology.Conference: 32nd Annual Meeting of the European Academy of Childhood Disability, EACD.Virtual 62(SUPPL 4), pp. 59
**Abstract:** Introduction: UK children's hospices offer respite and end-of-life care. Survival of young people with life-limiting conditions into adulthood has presented challenges as adult hospices predominantly only provide end of life care. Consequently, children's hospices have extended their age range. However, there are concerns about the suitability and sustainability of this approach. This study evaluated an innovative collaboration between a children's and adult hospice. The intervention was a monthly, half-day social/workshop-type session at the adult hospice. Run on an annual cycle, it sought to develop self-determination and social skills, support continuity of care, offer experiences of an adult hospice, and allow adult hospice staff the experience of working with young adults.

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14. **Supporting adults living with mucopolysaccharide (MPS) diseases: Understanding current experiences and future challenges.**
**Item Type:** Journal Article
**Authors:** Thomas, S. and Morrison, A.
**Publication Date:** 2020
**Journal:** Molecular Genetics and Metabolism.Conference: WORLDSymposium.Hyatt Regency, Orlando United States 129(2), pp. S151
**Abstract:** Mucopolysaccharidosis (MPS) diseases are rare, inherited metabolic disorders caused by lysosomal enzyme deficiency. They are life-limiting, progressively debilitating conditions. There is no curative treatment but novel therapies to slow progression and improvements in care have resulted in more people living into adulthood. Information about how adults are affected by MPS disease is limited. This study aimed to understand the challenges encountered by adults living with MPS disease and how best to support them with their condition. Members of the MPS Society were invited to take part in an online survey investigating their views about living with MPS diseases. Qualitative data was collected between September-October 2018. Data included in this analysis comprise a subset of responses from adults (aged 16 years and over) with MPS. Responses were analysed by applying an inductive thematic-content approach. Twenty-seven adults with MPS I (Hurler, Hurler Scheie, Scheie; 30%), MPS II (Hunter; 15%); MPS IV (Morquio; 48%) and MPS VI (Maroteaux Lamy; 7%) were included in this

study. Age categories ranged between 16-64 years. The most common challenges reported by participants were loss of mobility/being unable to perform every-day tasks (37%), coming to terms with their condition (19%), being unable to find a job (15%) and losing their cognitive capabilities (7%). Over a quarter of participants were worried about getting older and how the progressive deterioration of their functions would affect them in the future (30%). Participants would welcome support with accessing funding for managing their health and housing (19%), finding MPS medical specialists (11%), receiving information about adult services (7%) and improving provision of psychological care (7%). Adults with MPS diseases face on-going difficulties and future uncertainties as they age with their condition. The provision of support tailored to individual needs would be important to improve their quality of life and mental well-being.

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15. **Transition from pediatric to adult care for young adults with chronic respiratory disease.**
**Item Type:** Journal Article
**Authors:** Willis, L. D.
**Publication Date:** 2020
**Journal:** Respiratory Care 65(12), pp. 1916-1922
**Abstract:** Advances in medicine and technology have led to improved survival rates of children with chronic respiratory disease such as cystic fibrosis, neuromuscular disease, and ventilator dependence. Survival into adulthood has created the need for adult specialists for conditions originating in childhood. Transition from pediatric to adult health care is a process that requires advanced planning and preparation and is not a one-time transfer event. Transition should be standard practice, but many children with special health care do not experience successful transition outcomes. Barriers to successful transition include lack of a standardized process, inadequate planning, and poor communication. Adverse outcomes have occurred in cases of abrupt or haphazard transfers. A successful transition process includes early introduction and ongoing discussion that engages the adolescent to plan and prepare for the eventual transfer of care. Care responsibilities should be gradually shifted from the parent to the adolescent in a manner appropriate for the adolescent's age and developmental status. Good communication and collaboration between pediatric and adult care teams is crucial to ensure a smooth transfer of care. Incorporating the 6 core elements of transition can be helpful in developing a successful transition program. This narrative review summarizes the literature for health care transition from pediatric to adult care including the rationale, barriers, factors associated with successful transition, and special considerations. The intent of this review is to increase cli-nician awareness of health care transitions and the components necessary for an effective transfer of young adults with chronic respiratory disease. Understanding the transition process is an important consideration for both pediatric and adult clinicians, including respiratory therapists.

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16. **Multiple and multidimensional life transitions in the context of life-limiting health conditions: longitudinal study focussing on perspectives of young adults, families and professionals.**
**Item Type:** Journal Article
**Authors:** Jindal-Snape, Divya;Johnston, Bridget;Pringle, Jan;Kelly, Timothy B.;Scott, Rosalind;Gold, Libby and Dempsey, Raymond
**Publication Date:** Mar 25 ,2019
**Journal:** BMC Palliative Care 18(1), pp. 30
**Abstract:** BACKGROUND: There is a dearth of literature that investigates life transitions of young adults (YAs) with life-limiting conditions, families and professionals. The scant literature that is available has methodological limitations, including not listening to the voice of YAs, collecting data retrospectively, at one time point, from one group's perspective and single case studies. The aim of this

study was to address the gaps found in our literature review and provide a clearer understanding of the multiple and multi-dimensional life transitions experienced by YAs and significant others, over a period of time. METHODS: This qualitative study used a longitudinal design and data were collected using semi-structured interviews over a 6-month period at 3 time points. Participants included 12 YAs with life-limiting conditions and their nominated significant others (10 family members and 11 professionals). Data were analysed using a thematic analysis approach. RESULTS: Life transitions of YA and significant others are complex; they experience multiple and multi-dimensional transitions across several domains. The findings challenge the notion that all life transitions are triggered by health transitions of YAs, and has highlighted environmental factors (attitudinal and systemic) that can be changed to facilitate smoother transitions in various aspects of their lives. CONCLUSIONS: This study makes a unique and significant contribution to literature. It provides evidence and rich narratives for policy makers and service providers to change policies and practices that are in line with the needs of YAs with life-limiting conditions as they transition to adulthood. Families and professionals have specific training needs that have not yet been met fully.

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17. **Transition to adult care in young people with neuromuscular disease on non-invasive ventilation.**
**Item Type:** Journal Article
**Authors:** Onofri, Alessandro;Tan, Hui-Leng;Cherchi, Claudio;Pavone, Martino;Verrillo, Elisabetta;Ullmann, Nicola;Testa, Maria Beatrice Chiarini and Cutrera, Renato
**Publication Date:** Jul 23 ,2019
**Journal:** Italian Journal of Pediatrics 45(1), pp. 90
**Abstract:** BACKGROUND: Long-term mechanical ventilation (LTV) with non-invasive ventilation (NIV) prolongs survival in patients with Neuromuscular Diseases (NMDs). Transition from paediatric to adult healthcare system is an undervalued and challenging issue for children with chronic conditions on mechanical ventilation. METHODS: this retrospective study aims to compare issues of young adults in age to transition to adult care (>= 15 years old) affected by NMDs on NIV in two different Paediatric Respiratory Units in two different countries: Bambino Gesu Children's Hospital, Research Institute, (Rome, Italy) (BGCH) and the Paediatric Respiratory Unit of the Royal Brompton Hospital (London, UK) (RBHT). RESULTS: The median (min-max) age at starting ventilation was significantly different in the two groups (16 years old vs 12, p = 0.0006). We found significant difference in terms of median age at the time of observation (18 (15-22) vs 17 (15-19) years, p = 0.0294) and of type of referral (all the patients from the BGCH group were referred to paediatric services (n = 15, 100%), median age 18 (15-22); only 6 patients, in the RBHT group, with a median age 15.50 (15-17) years, were entirely referred to paediatric service). We found different sleep-disordered breathing assessments 6 full Polysomnography's, 7 Cardio-Respiratory Polygraphies and 2 oximetry with capnography ($SpO_2$-$tcCO_2$) studies in the BCGH group, while all patients of RBHT group were assessed with an $SpO_2$-$tcCO_2$ study. All patients from both groups underwent multidisciplinary assessment. CONCLUSIONS: In conclusion, patients with NMDs on NIV in age to transition to adult require complex multidisciplinary management: significant efforts are needed to achieve the proper transition to adult care.

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18. **The specification, acceptability and effectiveness of respite care and short breaks for young adults with complex healthcare needs: protocol for a mixed-methods systematic review.**
**Item Type:** Journal Article
**Authors:** Pilkington, Gerlinde;Knighting, Katherine;Bray, Lucy;Downing, Julia;Jack, Barbara A.;Maden, Michelle;Mateus, Ceu;Noyes, Jane;O'Brien, Mary R.;Roe, Brenda;Tsang, Anthony and Spencer, Sally
**Publication Date:** 2019
**Journal:** BMJ Open 9(6), pp. e030470

**Abstract:** INTRODUCTION: The number of young adults with complex healthcare needs due to life-limiting conditions/complex physical disability has risen significantly as children with complex conditions survive into adulthood. Respite care and short breaks are an essential service, however, needs often go unmet after the transition to adult services, leading to a significant impact on the life expectancy and quality of life for this population. We aim to identify, appraise and synthesise relevant evidence to explore respite care and short breaks provision for this population, and to develop a conceptual framework for understanding service models. METHODS AND ANALYSIS: A mixed-methods systematic review conducted in two stages: (1) knowledge map and (2) evidence review. We will comprehensively search multiple electronic databases; use the Citations, Lead authors, Unpublished materials, Google Scholar, Theories, Early examples, and Related projects (CLUSTER) approach, search relevant websites and circulate a 'call for evidence'. Using the setting, perspective, intervention/phenomenon of interest, comparison and evaluation framework, two reviewers will independently select evidence for inclusion into a knowledge map and subsequent evidence review, extract data relating to study and population characteristics, methods and outcomes; and assess the quality of evidence. A third reviewer will arbitrate where necessary. Evidence will be synthesised using the following approaches: quantitative (narratively/conducting meta-analyses where appropriate); qualitative (framework approach); policy and guidelines (documentary analysis informed approach). An overall, integrated synthesis will be created using a modified framework approach. We will use Grading of Recommendations Assessment, Development and Evaluation (GRADE)/GRADE-Confidence in the Evidence from Reviews of Qualitative Research to assess the strength and confidence of the synthesised evidence. Throughout, we will develop a conceptual framework to articulate how service models work in relation to context and setting. ETHICS AND DISSEMINATION: Ethical approval is not required as this is a systematic review. We will present our work in academic journals, at appropriate conferences; we will disseminate findings across networks using a range of media. Steering and advisory groups were established to ensure findings are shared widely and in accessible formats. PROSPERO REGISTRATION NUMBER: CRD42018088780. Copyright © Author(s) (or their employer(s)) 2019. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

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19. **"Getting ready for the adult world": how adults with spinal muscular atrophy perceive and experience healthcare, transition and well-being**
**Item Type:** Journal Article
**Authors:** Wan, Hamish W. Y.;Carey, Kate A.;D'Silva, Arlene;Farrar, Michelle A. and Kasparian, Nadine A.
**Publication Date:** 2019
**Journal:** Orphanet Journal of Rare Diseases 14(1), pp. N.PAG
**Abstract:** Background: Spinal muscular atrophy (SMA) has profound implications across a lifetime for people with the condition and their families. Those affected need long-term multidisciplinary medical and supportive care to maintain functional mobility, independence and quality of life. Little is known about how adults with SMA experience healthcare, or the components of care perceived as important in promoting well-being. The purpose of this study was to use qualitative research methodology to explore the lived experiences of healthcare and wellbeing of adults with SMA. Purposive sampling was used to recruit adolescents and adults with SMA, their parents and partners. Face-to-face or telephone-based semi-structured interviews were recorded and analysed using inductive thematic analysis. Results: Across a total of 25 interviews (19 people with SMA, 5 parents, 1 partner) many participants described disengagement from health services and major gaps in care throughout adulthood. Disengagement was attributed to the perceived low value of care, as well as pragmatic, financial and social barriers to navigating the complex healthcare system and accessing disability services. Adults with SMA valued healthcare services that set collaborative goals, and resources with a

positive impact on their quality of life. Mental health care was highlighted as a major unmet need, particularly during times of fear and frustration in response to loss of function, social isolation, stigma, and questions of self-worth. Alongside this, participants reported resilience and pride in their coping approaches, particularly when supported by informal networks of family, friends and peers with SMA. Conclusions: These findings provide insight into the lived experiences, values and perspectives of adults with SMA and their carers, revealing major, ongoing unmet healthcare needs, despite many realising meaningful and productive lives. Findings indicate the necessity of accessible, patient- and family-centered multidisciplinary care clinics that address currently unmet physical and mental health needs. Understanding the lived experiences of people with SMA, particularly during times of transition, is critical to advancing health policy, practice and research. Future studies are needed to quantify the prevalence, burden and impact of mental health needs whilst also exploring potential supportive and therapeutic strategies.

**DOI:** https://libkey.io/10.1186/s13023-019-1052-2

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20. **Duchenne and Becker muscular dystrophy in adolescents: Current perspectives.**
**Item Type:** Journal Article
**Authors:** Andrews, J. G. and Wahl, R. A.
**Publication Date:** 2018
**Journal:** Adolescent Health, Medicine and Therapeutics 9, pp. 53-63
**Abstract:** Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) are life-limiting and progressive neuromuscular conditions with significant comorbidities, many of which manifest during adolescence. BMD is a milder presentation of the condition and much less prevalent than DMD, making it less represented in the literature, or more severely affected individuals with BMD may be subsumed into the DMD population using clinical cut-offs. Numerous consensus documents have been published on the clinical management of DMD, the most recent of which was released in 2010. The advent of these clinical management consensus papers, particularly respiratory care, has significantly increased the life span for these individuals, and the adolescent years are now a point of transition into adult lives, rather than a period of end of life. This review outlines the literature on DMD and BMD during adolescence, focusing on clinical presentation during adolescence, impact of living with a chronic illness on adolescents, and the effect that adolescents have on their chronic illness. In addition, we describe the role that palliative-care specialists could have in improving outcomes for these individuals. The increasing proportion of individuals with DMD and BMD living into adulthood underscores the need for more research into interventions and intricacies of adolescence that can improve the social aspects of their lives.

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21. **The relationship between adolescents, in palliative care, and the cyberspace: An ethnographic model.**
**Item Type:** Journal Article
**Authors:** Borghi, C. A. and Szylit, R.
**Publication Date:** 2018
**Journal:** Palliative Medicine Conference, pp. 10th
**Abstract:** Background: To take care of adolescents with some life limiting and / or long threatening disease we must take some importance into the fact that in this period the adolescent will pass through two transitions - the infant stage to adulthood and the pediatric treatment for to adult. all these changes in a life of a adolescent in palliative care can affect the social and psychological development.

Cyberspace has become an alternative social space, causing a great technological, social and cultural change in society, especially for adolescents, becoming a very important tool in their lives.

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22. **Introducing advance care planning into the transition process: The achd patient perspective.**
**Item Type:** Journal Article
**Authors:** Edwards, L. A.;Hansen, K.;Sillman, C.;Dong, E.;Scribner, C.;Romfh, A.;Lui, G. K. and Fernandes, S. M.
**Publication Date:** 2018
**Journal:** Circulation Conference: 2018 American Heart Association Scientific Sessions. Chicago, IL United States: November 2018
**Abstract:** Introduction: The goal of the transition process from pediatric to adult care for congenital heart disease (CHD) patients, in additional to uninterrupted care, is to educate adolescents and young adults (AYAs) about their health and encourage them to develop strong self-care, decision-making, and communication skills. Adults are expected to voice their own values, opinions, and healthcare goals, especially when it comes to end-of-life (EOL) care, and, thus, it has been suggested to introduce advance care planning (ACP) into the transition process. To help inform timing of first ACP, we asked ACHD patients to share their opinions.

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23. **How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability**
**Item Type:** Journal Article
**Authors:** Gauthier-Boudreault, Camille;Couture, Mélanie and Gallagher, Frances
**Publication Date:** 2018
**Journal:** Journal of Applied Research in Intellectual Disabilities 31, pp. 215-223
**Abstract:** Background: At age 21, access to specialised services for youth with profound intellectual disability is reduced. Few studies have focused on parents' views concerning potential solutions to ease the transition to adulthood, and most existing solutions target young adults with less severe intellectual disability. The aim of this study is to propose realistic solutions to meet the needs of young adults with profound intellectual disability and their families during and after the transition to adulthood. Method: Using a descriptive qualitative design, two individual semi-structured interviews were conducted with 14 parents. Results: Ideas for innovative solutions included responses to parents' informational, material, intellectual and emotional needs during and after transition period. The majority of these solutions involve knowledge sharing, improved inter-institutional collaboration and social participation of young adults, and offering parents emotional support. Conclusion: Some solutions could be implemented within existing transition planning programs, based on their strengths and limitations.

**DOI:** https://libkey.io/10.1111/jar.12394

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24. **Evaluation of a pilot service to help young people with life-limiting conditions transition from children's palliative care services**
**Item Type:** Journal Article
**Authors:** Hutcheson, Sinead;Maguire, Hilary and White, Clare
**Publication Date:** 2018
**Journal:** International Journal of Palliative Nursing 24(7), pp. 322-332
**Abstract:** Background: When young people with life-limiting diagnoses become too old for children's

hospice services, they often experience challenges transitioning into adult services. A two-year pilot project was developed to try to aid transitioning, which involved a day service with occasional overnight trips. Aim: To evaluate the pilot project. Method: Three focus groups made up of key stakeholders (young people, their parents and staff) were set up and analysed using an adopted thematic analysis framework. Results: The participants consisted of three young people, seven parents and six staff members. Participants described the transition period as a difficult time for both young people and their families, with a perceived lack of adult services available. All groups agreed that the pilot had a positive impact on young people and their families and all were keen for the project to continue. Conclusion: This pilot models a service that could be adopted by other organisations in order to aid the transition between child and adult hospice services, with further potential for application in mental health and special needs services.

**DOI:** https://libkey.io/10.12968/ijpn.2018.24.7.322

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25. **The consumer voice: Using co-design to improve transitions across the healthcare continuum**
**Item Type:** Journal Article
**Authors:** Johnson, Hannah; Moss, Perrin; Callard, Nicola; Hoyland, Margaret; Usher, Helen-Louise; Henney, Roslyn; Seear, Lynne and Newcomb, Dana
**Publication Date:** 2018
**Journal:** International Journal of Integrated Care (IJIC) 18, pp. 1-2
**Abstract:** Background: Transition of care can encompass many different types of journeys. This includes moving between health professionals, between age-specific services, and/or clinical settings. Various preventable adverse events are reported to be higher when patients are moving between care settings and health professionals. For example when moving from acute care settings, there may be an incomplete transfer of information, patient confusion and lack of clear ownership or accountability of outcomes. Patient and family-centred care is a key dimension of high quality and safe care, which leads to improved health outcomes, satisfaction of care, prevention of future adverse outcomes, and reduction of readmissions to hospital. Aims and Objectives: This workshop aims to explore consumer's experiences in the following examples of transitions of care: A child transitioning to an adolescent; medical, mental health and social needs; healthcare, disability and social services. A young person transitioning into school (kindy, primary school, high school, new school, special school or mainstream school. An adolescent transitioning to an adult; medical, mental health and social needs; healthcare, disability and social services; service age cut-offs. Transitioning from primary care services to tertiary care services and back again. Transitioning from being unwell, to being well, to potentially being unwell again; e.g. chronic diseases, cancer. The objectives of the workshop are: Share consumer experiences of various transitions of care episodes to highlight importance of the consumer voice. Develop awareness about the importance of the consumer-voice and the benefits of co-design. Workshop innovative ideas and potential solutions for improving transition of care with consumers. Format: 2 consumers present their real life scenarios to a captive audience of delegates for the first 25 mins (10 minutes each). Five post-it notes/butcher's paper will be set up around the room, each addressing one of the five transitions of care examples (listed under in the 'Aim' section). Each station will have a consumer or two who have a personal situation that is relevant to the topic. The audience would be asked to split up into the five stations and workshop the transitional issue by collaborating with their colleagues. They will be asked to identify the issues, either raised by the consumer, and more issues they can think of, and brainstorm potential integrated care solutions; in collaboration with the consumer who is present. Each station can present a summary of their brainstorming to the wider group. Target Audience: All delegates interested in working with consumers to improve their care journey. Learnings/Take away: To recognise: The benefits of co-design to address consumer needs and

concerns. How co-design can improve the way a service delivers care from patient outcome and satisfaction perspective. How rewarding the work can be for health professionals when patient outcomes and satisfaction are realised through co-design and patient and family-centred care.

**DOI:** https://libkey.io/10.5334/ijic.s1099

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26. **Facilitating transition from children's to adult services for young adults with life-limiting conditions (TASYL): Programme theory developed from a mixed methods realist evaluation.**
**Item Type:** Journal Article
**Authors:** Kerr, Helen; Price, Jayne; Nicholl, Honor and O'Halloran, Peter
**Publication Date:** Oct ,2018
**Journal:** International Journal of Nursing Studies 86, pp. 125-138
**Abstract:** BACKGROUND: Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood, necessitating a transition from children's to adult services. Given the lack of evidence on interventions to promote transition, it is important that those creating and evaluating interventions develop a theoretical understanding of how such complex interventions may work. OBJECTIVES: To develop theory about the interventions, and organisational and human factors that help or hinder a successful transition from children's to adult services, drawing on the experience, knowledge, and insights of young adults with life-limiting conditions, their parents/carers, and service providers. DESIGN: A realist evaluation using mixed methods with four phases of data collection in the island of Ireland. Phase one: a questionnaire survey of statutory and non-statutory organisations providing health, social and educational services to young adults making the transition from children's to adult services in Northern Ireland and one Health Services Executive area in the Republic of Ireland. Phase two: interviews with eight young adults. Phase three: two focus groups with a total of ten parents/carers. Phase four: interviews with 17 service providers. Data were analysed seeking to explain the impact of services and interventions, and to identify organisational and human factors thought to influence the quality, safety and continuity of care. RESULTS: Eight interventions were identified as facilitating transition from children's to adult services. The inter-relationships between these interventions supported two complementary models for successful transition. One focused on fostering a sense of confidence among adult service providers to manage the complex care of the young adult, and empowering providers to make the necessary preparations in terms of facilities and staff training. The other focused on the young adults, with service providers collaborating to develop an autonomous young adult, whilst actively involving parents/carers. These models interact in that a knowledgeable, confident young adult who is growing in decision-making abilities is best placed to take advantage of services - but only if those services are properly resourced and run by staff with appropriate skills. No single intervention or stakeholder group can guarantee a successful transition. Rather, service providers could work with young adults and their parents/carers to consider desired outcomes, and the range of interventions, in light of the organisational and human resources available in their context. This would allow them to supplement the organisational context where necessary and select interventions that are more likely to deliver outcomes in that context. Copyright © 2018 The Authors. Published by Elsevier Ltd.. All rights reserved.

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27. **Making a 'JUMP' from paediatric to adult healthcare: A transitional program for young adults with chronic neurological disease.**
**Item Type:** Journal Article
**Authors:** Mc Govern, E. M.;Maillart, E.;Bourgninaud, M.;Manzato, E.;Guillonnet, C.;Mochel, F.;Bourmaleau, J.;Lubetzki, C.;Baulac, M. and Roze, E.

**Publication Date:** 2018
**Journal:** Journal of the Neurological Sciences 395, pp. 77-83
**Abstract:** Background: "JUMP" is a multidisciplinary program based at the Pitie-Salpetriere Hospital Paris that transitions young adults with chronic neurological conditions from paediatric to adult healthcare. Transitional care programs have been shown to improve medical, educational and psychosocial outcomes for adolescent patients.

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28. **Changing landscape of paediatric palliative care.**
**Item Type:** Journal Article
**Authors:** Nallapeta, N. and Hills, M.
**Publication Date:** 2018
**Journal:** Developmental Medicine and Child Neurology Conference, pp. 30th
**Abstract:** Introduction: Advancement in medical science and better health care has led to increased survival of children with complex neurodisability (cerebral palsy, neuromuscular, neuro-metabolic, and genetic disorders). Paediatric palliative care has traditionally been associated with looking after children with oncological conditions. This study looked into the role of hospices in children and young adults with complex neurodisability. Patients and method: A retrospective review of electronic case records looking at all admission (3 months period) to Martin House Children's Hospice (provides family-led care for families from across West, North, and East Yorkshire) was performed.

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29. **Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services**
**Item Type:** Journal Article
**Authors:** Noyes, Jane; Pritchard, Shan; Pritchard, Aaron; Bennett, Virginia and Rees, Sally
**Publication Date:** 2018
**Journal:** Journal of Advanced Nursing (John Wiley & Sons, Inc.) 74(12), pp. 2871-2881
**Abstract:** Aims: The aim of this study was to report a secondary qualitative analysis exploring the cultural and practical differences that young people and parents experience when transitioning from children's to adult services. Background: Despite two decades of research and quality improvement initiatives, young people with life-limiting and life-threatening conditions still find transition unsatisfactory. Design: Secondary analysis: 77 qualitative interviews with children and young people (20), parents (35), siblings (1), professionals (21). Methods: Qualitative framework analysis completed 2017. Findings: Six conflicting realities were identified: Planning to live and planning to die with different illness trajectories that misaligned with adult service models; being treated as an adult and the oldest "patient" in children's services compared with being treated as a child and the youngest "patient" in adult services; being a "child" in a child's body in children's services compared with being a "child" in an adult's body in adult services for those with learning impairments; being treated by experienced children's professionals within specialist children's services compared with being treated by relatively inexperienced professionals within generalist adult services; being relatively one of many with the condition in children's services to being one of very few with the condition in adult services; meeting the same eligibility criteria in children's services but not adult services. Conclusion: Inequity and skills deficits can be addressed through targeted interventions. Expanding age-specific transition services, use of peer-to-peer social media, and greater joint facilitation of social support groups between health services and not-for-profit organizations may help mitigate age dilution and social isolation in adult services

**DOI:** https://libkey.io/10.1111/jan.13811

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30 **Qualitative accounts of young-people, parents and staff involved with a purpose-designed, pilot short-break service for 18–24 year olds with life-limiting conditions**
**Item Type:** Journal Article
**Authors:** Young, Lynne;Egdell, Angela and Swallow, Veronica

**Publication Date:** 2018
**Journal:** Children & Youth Services Review 86, pp. 142-150
**Abstract:** Purpose Transition to adult health and social-care services is a time of great uncertainty for young adults with life-limiting conditions; due to improved management, many who would have previously died before they were 18 years old are now surviving into early adulthood. Nevertheless, few services exist to meet their specific needs for specialist short breaks away from home. The purpose of this research was to determine the views and perspectives of young adults' parents/carers and staff engaged with a purpose-designed, pilot short-break service for 18–24 year olds with life-limiting conditions. Data were gathered through qualitative individual or focus group interviews involving two young adults, four mothers and fifteen health or social-care staff associated with the service. Data were analysed using Framework Analysis. Principal results Emergent themes: (i) The need for a specialist short-break service; (ii) Decision making when using or delivering the service; (iii) Challenges of staffing and financing the service (iv) Meeting young adults' complex needs and preferences (v) Suggestions for how to improve the service. The young adults described how they benefitted from access to specialist, age-appropriate, on-site clinical skills facilities and opportunities to socialise with peers. Mothers said they benefitted from time alone or with other family members in the knowledge that the specialist short break service met the needs and preferences of their child as they made the transition to adult services. However, all participating mothers and staff expressed concern about the future well-being of young adults when they left the service at 24 years old. Major conclusions This study provides new information to inform ongoing development of short-break services for the increasing number of young adults with life-limiting conditions who are surviving longer than they would previously have done. This will help to ensure that UK services are responsive to users' needs and preferences.

**DOI:** https://libkey.io/10.1016/j.childyouth.2018.01.016

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31. **The transition of patients with rare diseases between providers: the patient journey from the patient perspective**
**Item Type:** Generic
**Author:** Ferrara, Lucia, Morando, Verdiana and Tozzi, Valeria
**Publication Date:** 2017
**Publication Details:** International Journal of Integrated Care (IJIC), 17, pp.1-2. Ubiquity Press.
**Abstract:** Background: Rare diseases are a group of more than 6000 disorders that on the whole may affect 30 million European Union citizens. Most rare diseases are of genetic origin, are often chronic and life-threatening. Patients living with rare diseases typically receive care from many providers and move frequently within health care settings, so high-quality transitional care is especially important for them, as well as for their family caregivers. Poor communications, incomplete transfer of information, inadequate education of health professionals, limited access to expertise services, and the absence of a single point person to ensure continuity of care all contribute to gaps in care during transitions. The research project focuses on four rare Lysosomal storage disease - LSDs (Pompe disease, Anderson-Fabry disease, Gaucher disease and Mucopolysaccharidosis type 1) featured by the availability of treatments that allow for a good quality of life for patients and aims to gather information on the real patient journey and on the health and social services used in order to analyse and identify the key conditions for improving the care management of rare and ultrarare diseases (RD). Methods: We

conducted a national survey, distributed to patients and caregivers from the 1st of June 2016 to the 7th of August 2016. Data were gathered through questionnaires disseminated online (through the patient associations' websites, Facebook pages and other online networks) or administered directly to patients through the patients' associations, to maintain the privacy and anonymity. The questionnaire consisted of 70 questions related to history and pattern of referrals to specialist, time to diagnosis, core medical tests, disciplines and specialists, time and type of treatment. The questionnaire was developed based on 16 in-depth interviews to patients sampled to cover the 4 LSDs, different ages and residence at the national level and further tested through the support of patients' associations. Data were analysed by descriptive and analytical statistics. Results: Of the survey participants, 177 patients provided evaluable data. The sample covered the national territory, was mainly composed of adult patients (average 40 age), who were diagnosed with rare LSDs 13 years ago. According to the survey patients living with rare LSD diseases visited an average of 2.4 centres before receiving an accurate diagnosis and the mean length of time from symptom onset to accurate diagnosis was around 7.3 years, however, there was a significant relationship between mean length of time for diagnosis and age (P >0.001), the mean length of time was reduced to 1.5 years for young patients (under 20 age), while was around 12 years for the older ones (over 65 age), indicating therefore the clear improvement in the diagnostic phase and in the access to reference centres. The analysis revealed the variability in tackling rarity and complexity, the wide number and specialization of professionals involved and the difficulty to provide integrated care pathways (ICPs) due to the lack of scalability and standardisation of care processes. Conclusion: The combination of rarity, complexity and lack of effective treatment creates huge obstacles to the provision of holistic care and in many cases significant medical, psychological and social needs remain unmet. Rare and ultra-rare disease challenge the most traditional care management models, indeed, people with a RD often need follow up care and support from different categories of health professionals, often from several different medical specialities, as well as by social workers and other social and local service providers which requires a level of coordination not easy to organise in most health care systems.

**DOI:** https://libkey.io/10.5334/ijic.3465

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32. **Transition from children’s to adult services for young adults with life-limiting conditions: A realist review of the literature**
**Item Type:** Journal Article
**Authors:** Kerr, Helen; Price, Jayne; Nicholl, Honor and O’Halloran, Peter
**Publication Date:** 2017
**Journal:** International Journal of Nursing Studies 76, pp. 1-27
**Abstract:** Background Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood, which means they must make the transition from children’s to adult services. This has proved a challenging process for both young adults and service providers, with complex transition interventions interacting in unpredictable ways with local contexts. Objectives To explain how intervention processes interact with contextual factors to help transition from children’s to adult services for young adults with life-limiting conditions. Design Systematic realist review of the literature. Data sources Literature was sourced from four electronic databases: Embase, MEDLINE, Science Direct and Cochrane Library from January 1995 to April 2016. This was supplemented with a search in Google Scholar and articles sourced from reference lists of included papers. Review methods Data were extracted using an adapted standardised data extraction tool which included identifying information related to interventions, mechanisms, contextual influences and outcomes. Two reviewers assessed the relevance of papers based on the inclusion criteria. Methodological rigor was assessed using the relevant Critical Appraisal Skills Programme tools. Results 78 articles were included in the

review. Six interventions were identified related to an effective transition to adult services. Contextual factors include the need for children's service providers to collaborate with adult service providers to prepare an environment with knowledgeable staff and adequate resources. Mechanisms triggered by the interventions include a sense of empowerment and agency amongst all stakeholders. Conclusions Early planning, collaboration between children's and adult service providers, and a focus on increasing the young adults' confidence in decision-making and engaging with adult services, are vital to a successful transition. Interventions should be tailored to their context and focused not only on organisational procedures but on equipping young adults, parents/carers and staff to engage with each other effectively.

**DOI:** https://libkey.io/10.1016/j.ijnurstu.2017.06.013

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33. **Enablers and barriers of men with Duchenne muscular dystrophy transitioning from an adult clinic within a pediatric hospital.**
**Item Type:** Journal Article
**Authors:** Lindsay, S.;McAdam, L. and Mahendiran, T.
**Publication Date:** 2017
**Journal:** Disability and Health Journal 10(1), pp. 73-79
**Abstract:** Background Young men with Duchenne muscular dystrophy (DMD) live into adulthood and need specialized care. However, services for adults are fragmented. We know little about young men's experiences, their parents, and clinicians who support them as they transition to adult care. Objective To explore the enablers and barriers of clinicians, young men, and parents as they transition from an adult DMD clinic within a pediatric hospital to an adult health facility. Methods We conducted semi-structured, in-depth interviews with 16 participants (7 clinicians, 5 parents, 4 youth). We used an open-coding, thematic approach to analyze the data. Results Clinicians, youth and their parents experienced several enablers and barriers in transitioning to an adult health care center. Clinicians reported that structural factors including leadership and advocacy supported the transition. Clinicians and parents found that the availability and continuity of care both enabled and hindered the transition. Parents and youth conveyed the difficulties of adjusting to the different model of adult care and also accessing resources. All participants described how relational factors (i.e., effective communication and family involvement) enabled the transition. On an individual level, clinicians, parents and youth viewed transition readiness and other life skill supports as an enabler and a barrier to transitioning. All participants reported the difficulties of maintaining mental health for youth with DMD transitioning to adult health care. Conclusions Clinicians, youth, and parents experienced several enablers and barriers in transitioning to adult health care. Further work is needed to understand the complex transition needs of youth with DMD.

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34. **Taking on choice and control in personal care and support: The experiences of physically disabled young adults**
**Item Type:** Journal Article
**Authors:** Mitchell, Wendy; Beresford, Bryony; Brooks, Jenni; Moran, Nicola and Glendinning, Caroline
**Publication Date:** 2017
**Journal:** Journal of Social Work 17(4), pp. 413-433
**Abstract:** Summary Research on self-directed care has focused on older people and adults with learning or mental health difficulties. This article reports physically disabled young adults' experiences of self-directed care. Such work is important because young adults are a 'minority' group within adult social care. This, and their still developing life-skills and lack of life experience, may have a bearing on

their experiences of self-directed care and associated support needs. An exploratory qualitative study using semi-structured interviews investigated this issue. Participants were 19–29 years with a range of congenital and acquired impairments. Findings Many aspects of interviewees' experiences of self-directed care appeared to be influenced by their limited life experience, the fact they are still developing life-skills and are a minority group within adult social care. Interviewees identified their lack of life experience and self-confidence as making them cautious in assuming responsibility for their care arrangements and, typically, their desire for on-going parental support. They also believed their age and life stage contributed to difficulties managing carers and PAs. Preferences around characteristics of carers/PAs were influenced by their age and desire to integrate into mainstream activities. Information provided by statutory services did not (fully) acknowledge that some users were young adults. Applications Compared to other physically disabled users of adult social care, young adults' under-developed life-skills and lack of life experience influences their experiences as users, and the support they needed to assume control of their care arrangements. Tailored information and support for this 'minority group' is required.

**DOI:** https://libkey.io/10.1177/1468017316644700

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### 35. EXPLORATION OF ADULT HOSPICES AS A SHORT BREAK PROVIDER FOR YOUNG ADULTS WITH PALLIATIVE CARE NEEDS.

**Item Type:** Journal Article
**Authors:** Finlayson, H.
**Publication Date:** 2016
**Journal:** BMJ Supportive and Palliative Care. Conference: People, Partnerships and Potential Conference. Liverpool United Kingdom 6(Supplement 1) (pp A40): November 2016
**Abstract:** Background * In the UK the number of 16-25 year olds living with life limiting illness has doubled in the past decade (Fraser et al., 2011). * Nationally there is a lack of suitable respite provision for young adults with palliative care needs (King and Barclay, 2007, p201). * An integrative literature review has been carried out to support development of a business case for a regional young adult short break unit in an adult hospice. * Short break provision is seen as integral to children's palliative care (Ling, 2012, p129) with many describing provision a "life line" (Jackson and Robinson, 2003, p105). Equivalent support does not exist in adult hospices. * NICE Guidelines for Transition (2016) recommend developmentally appropriate care provision Literature review-emerging themes Needs of parents: * A break from complex and technical care is needed, to maintain well-being and enable time with other children * A break enables parents to sustain care in the home * Needs change over time-ageing parents and relatives, increasing complexity of care means less informal support available * Parents struggle with trusting others to provide care. Needs of young adults: * Opportunities for valuable peer support * Opportunity for social activities * A break from family with opportunity to explore and increase independence from parents. Significant paucity in primary research with young adults Service delivery * Significant differences between children's and adult's hospice care-transition is challenging * Young adult short break models have high care needs and expensive staffing costs * Adult hospices lack experience in complex care needs of young adults-significant training needs. Conclusions * Significant respite needs for parents * Developmentally appropriate respite should be available * Children's hospices have often been the only provider able to meet these complex needs. Can adult hospices inherit this legacy for a new generation of young adults with palliative care needs surviving into adulthood? * Further primary research with young adults needed.

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**36. CLAN CLUB. CANCER, LEADING A NORMAL LIFE.**

**Item Type:** Journal Article

**Authors:** Howells, M.

**Publication Date:** 2016

**Journal:** BMJ Supportive and Palliative Care. Conference: People, Partnerships and Potential Conference. Liverpool United Kingdom 6(Supplement 1) (pp A61-A62), November 2016

**Abstract:** The St Luke's' Hospice Information Service provides information and support for individuals affected by cancer/life limiting illness at any stage of their journey. The Clan Club is a support group for children/young people aged 16-19 years with a cancer diagnosis ranging from diagnosis into survivorship and beyond. It also offers support to siblings and parents of children aged under six. There is no support group identified in Essex for this group of people. The group provides the youngsters with the opportunity to meet peers, get support from trained facilitators and more importantly have fun. There are indoor and outdoor activities available and the youngsters are encouraged to partake as they are able. In the summer months there is greater emphasis on being more physically active with the winter months being more suitable to board/electronic games and creative activities. From a Macmillan grant other activities are funded e.g. bowling. The adults have access to support for themselves. The sharing of information, hints and tips as well as managing the mire of tertiary care whilst ultimately getting the 'best' for their child are key themes of discussion. All the individuals that attend the group have the opportunity to be referred to hospice services. This can include counseling for children/young people and adults, complementary therapy as well as individualised carers' support and access to a menu of therapeutic groups. There are age-related outcome-based evaluations in place to measure the effectiveness of the group. All service users are encouraged to feedback any issues that would improve their experience of the group. There is no similar group in Essex to meet the support needs of this group of people. In essence the Clan Club is a warm, friendly group that values individuality, promotes empowerment, but most importantly provides a focus for families to meet.

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**37. Life transitions of adolescents and young adults with life-limiting conditions.**

**Item Type:** Journal Article

**Authors:** Johnston, B.;Jindal Snape, D. and Pringle, J.

**Publication Date:** 2016

**Journal:** International Journal of Palliative Nursing 22(12), pp. 608-617

**Abstract:** AIMS: A systematic review was conducted to appraise and classify evidence related to the life transitions of adolescents and young adults with life-limiting conditions. METHODS: The databases searched were MEDLINE, CINAHL, PsycINFO, Cancer Lit, and AMED. Methodological quality was assessed using an established tool and the final articles included in the study were rated as moderate to high quality. Articles were then assessed based on the insight that they provided into life transitions for adolescents and young adults. RESULTS: Eighteen studies were included in the final review, with two major life transitions identified as pertinent: 'illness transition' and 'developmental transition'. These concurrent transitions were found to be relevant to adolescents and young adults with life-limiting conditions, generating complex needs. Sub-themes within the transitions were also identified. Furthermore, the illness transition was found to also impact significant others, namely family members, having physical, mental and emotional health implications and requiring them to make adaptations. CONCLUSIONS: Future research is needed to focus on adolescent and young adult perspectives to bring further insight into these key transitions, since such perspectives are currently underrepresented. Attention to the impact of the illness on the whole family would be useful to expand findings from this review.

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38. **Understanding the relationship transitions and associated end of life clinical needs of young adults with life-limiting illnesses: A triangulated longitudinal qualitative study.**
**Item Type:** Journal Article
**Authors:** Johnston, B.;Jindal Snape, D.;Pringle, J.;Gold, L.;Grant, J.;Dempsey, R.;Scott, R. and Carragher, P.
**Publication Date:** 2016
**Journal:** SAGE Open Medicine 4(pagination), pp. ate of Pubaton: 2016
**Abstract:** Background: Care of young adults with life-limiting illnesses can often be complex due to the fact that they are growing and developing within the continuing presence of their illness. There is little research conducted nationally and internationally, which has examined the life issues of young adults or taken a longitudinal approach to understand such issues over a period of time.

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39. **Organisational factors affecting transition from children's to adult services by young adults with life-limiting conditions in Ireland.**
**Item Type:** Journal Article
**Authors:** Kerr, H.;Nicholl, H.;Price, J. and O'Halloran, P.
**Publication Date:** 2016
**Journal:** Palliative Medicine.Conference: 9th World Research Congress of the European Association for Palliative Care, EAPC 2016.Dublin Ireland 30(6), pp. NP120-NP121
**Abstract:** Research aims: To provide an overview of the transition services provided to young adults with life-limiting conditions in Ireland, identifying models of good practice and the factors influencing the quality and continuity of care. Study population: Service providers in statutory and non-statutory organisations providing care to young adults with life-limiting conditions; young adults with life-limiting conditions and their parents. Study design and methods: A realist evaluation approach using a mixed methods design with four phases of data collection: a questionnaire survey of health, social, educational and charitable organisations providing transition services to young adults in Northern Ireland and one Health Service Executive area in the Republic of Ireland with 104 individual responses from 29 organisations; interviews with eight young adults, two focus groups with parents/carers and 17 interviews with service providers. Method of analysis: Data from the survey, interviews and focus groups were thematically analysed seeking to explain the impact of services and interventions, and to identify organisational factors influencing the quality and continuity of care. The two jurisdictions were analysed separately and a comparative analysis undertaken.

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40. **Understanding the perspectives of young adults with duchenne muscular dystrophy as they transition to adulthood and adult health care.**
**Item Type:** Journal Article
**Authors:** Lindsay, S.;Mcadam, L. and Mahenderin, T.
**Publication Date:** 2016
**Journal:** Journal of Neuromuscular Diseases Conference, pp. 14th
**Abstract:** The majority of children with Duchenne Muscular Dystrophy now live into adulthood. Such young adults will have specialized health care needs that are unfamiliar to most adult health care providers. There are often several challenges encountered in the process of transitioning to adult health care including lack of readiness and lack of specialized health care providers. It is particularly critical to ensure that the proper mechanisms are in place as youth transition to adult care so that their health and well-being are not impacted. Adolescents and young adults with disabilities are often significantly underserviced in health and social care and many 'fall through the cracks' as they transition to adulthood. Such gaps in the system combined with inadequate transition arrangements are particularly

concerning because they are linked with poorer long-term health outcomes, increased hospitalizations and reduced opportunities to participate in the community. Although there is a growing literature on transitions to adult care, youth with Duchenne Muscular Dystrophy (DMD) have largely been neglected. Exploring this population is vital because they are now living well into adulthood and have different needs than other clinical groups. DMD is often seen as a pediatric disease associated with a corresponding lack of transition planning. Thus, youth with DMD may not have been empowered or supported in decision-making about their care and other aspects of their lives. It is critical, therefore, to understand youths' needs to inform the development of an effective transition pathway.

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**41. Access to respite and social care for young adults in Wales: Please mind the gap.**

**Item Type:** Journal Article

**Authors:** Lorton, C.;Davies, C.;Davies, A. C.;Tamlyn, P.;Fear, K.;Davies, S. and Lidstone, V.

**Publication Date:** 2016

**Journal:** Palliative Medicine.Conference: 9th World Research Congress of the European Association for Palliative Care, EAPC 2016.Dublin Ireland 30(6), pp. NP374

**Abstract:** Background: Young people with life-limiting conditions (LLC) constitute a new and growing population with distinct palliative care needs. As well as complex physical needs, these young adults and their families have particular needs for respite and social care Aim: To describe provision of respite and social care for young people with LLC across Wales Method: All health boards and councils in Wales were contacted with a request for information about respite and social care services provided to 18-30 year olds with LLC Care homes were also contacted about their services, registration availability of nursing care and activities Results: All 7 Health Boards and 22 Councils responded Response rate from care homes was very low. 2 care homes replied in full; 1 was registered to care for adults under age 40. Most health boards reported that only usual adult services are available. Just 1 health board reported providing respite for this group. 2 councils reported access to respite services with 24 hour nursing Discussion: Although essential for many young people with LLC, respite with 24 hour nursing care is frequently not available. Many respite and social services are targeted at people with learning disabilities and, in many cases, no distinction was made between services for people with learning disabilities and those without.

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**42. Short break and emergency respite care: what options for young people with life-limiting conditions?.**

**Item Type:** Journal Article

**Authors:** Mitchell, Tracy K.;Knighting, Katherine; O’Brien, Mary R. and Jack, Barbara A.

**Publication Date:** Feb ,2016

**Journal:** International Journal of Palliative Nursing 22(2), pp. 57-65

**Abstract:** BACKGROUND: Service providers face difficult decisions about how best to develop services for the increasing numbers of young people with life-limiting conditions who require palliative care. OBJECTIVE: To explore alternative short break and emergency respite care options to children's hospice care. METHODS: A two-phase evaluation with young people, families and professionals. Phase 1: qualitative semi-structured interviews and focus groups (n=53). Phase 2: mixed-method survey (n=82), qualitative findings only. RESULTS: There were few, or no, appropriate short break and emergency respite care alternatives when children's hospice care was not available that can meet the need of young people with life-limiting conditions, creating anxiety for children's hospice users and those leaving the service as a result of reaching transition age or through no longer meeting the children's hospice eligibility criteria. CONCLUSION: Access to appropriate short break and emergency respite care is required to prevent lifelong negative consequences for young people with life-limiting conditions, their family and society. Research is undoubtedly required to explore the impact and outcomes of children's hospice discharge for young people and their family. Particular attention should be paid to the lack of services for an increasing population making the transition from children's hospices.

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43. **Challenges and 'obstacles': reframing our perspective on the transition into adulthood for young people with life-limiting and life-threatening conditions.**
**Item Type:** Journal Article
**Authors:** Pritchard, A. W. and Rees, S. A.
**Publication Date:** 2016
**Journal:** Journal of the Royal College of Physicians of Edinburgh 46(4), pp. 223-227

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44. **Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition**
**Item Type:** Journal Article
**Authors:** Waldboth, Veronika;Patch, Christine;Mahrer-Imhof, Romy and Metcalfe, Alison
**Publication Date:** Oct ,2016
**Journal:** International Journal of Nursing Studies 62, pp. 44-59
**Abstract:** INTRODUCTION: The transition into adulthood is a developmental stage within the life cycle. A chronic childhood condition can disrupt this transition and create major challenges for both the young person and his or her family. Little is known about families' experiences when living with a rare genetic disease. Therefore, the purpose of this literature review was to understand experiences of families living with a chronic childhood disease during transition into adulthood by integrating evidence. METHOD: A systematic review using an integrative approach to data inclusion and analysis comprising qualitative, quantitative and other methodological studies about a range of genetic and chronic childhood diseases was undertaken to identify relevant information. Databases searched were PubMed, Cochrane Library, PsychINFO, CINAHL, and AMED, using the search terms (1) family, caregivers, young adult, adolescent; (2) adolescent development, transitional programs, transition to adult care; (3) muscular dystrophy, spinal muscular atrophy, cystic fibrosis, haemophilia and sickle cell disease. Study findings were critically appraised and analyzed using critical interpretive synthesis. RESULTS: A total of 8116 citations were retrieved. 33 studies remained following the removal of duplicates, papers unrelated to genetic childhood conditions and families' experiences of the transition into adulthood. Findings provided three perspectives: (1) the young person's perspective on how to "live a normal life in an extraordinary way" and "manage a chronic and life threatening disease"; (2) the parent perspective on the "complexity of being a parent of a chronically ill child" and "concerns about the child's future" and (3) the sibling perspective on "concerns about the siblings future". As a consequence of the genetic childhood condition, during the ill family members' transition into adulthood all family members were at risk for psychosocial difficulties as they mutually influenced each other. Previous research focused predominately on the individual illness experience, and less emphasis was put on the family perspective. CONCLUSIONS: Young people and their family members experienced multiple challenges and not only for the ill individual but also there were consequences and health risks for the whole family system. Therefore, a family systems perspective to research and care is indicated to assist affected families to cope with their complex life and health situation. Copyright © 2016 Elsevier Ltd. All rights reserved.

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45. **Long term non-invasive ventilation in children: Impact on survival and transition to adult care.**
**Item Type:** Journal Article
**Authors:** Chatwin, M.;Tan, H. L.;Bush, A.;Rosenthal, M. and Simonds, A. K.
**Publication Date:** 2015
**Journal:** PLoS ONE 10(5) 01 May 2015
**Abstract:** Background: The number of children receiving domiciliary ventilatory support has grown over the last few decades driven largely by the introduction and widening applications of non-invasive ventilation. Ventilatory support may be used with the intention of increasing survival, or to facilitate discharge home and/or to palliate symptoms. However, the outcome of this intervention and the number of children transitioning to adult care as a consequence of longer survival is not yet clear.

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46. **Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: a qualitative systematic review protocol.**
**Item Type:** Journal Article
**Authors:** Ekberg, Stuart; Bradford, Natalie; Herbert, Anthony; Danby, Susan and Yates, Patsy
**Publication Date:** Nov ,2015
**Journal:** JBI Database of Systematic Reviews and Implementation Reports 13(11), pp. 33-42
**Abstract:** REVIEW QUESTION/OBJECTIVE: The objective of this review is to identify and synthesize the best international qualitative evidence on healthcare users' experiences of communication with healthcare professionals about children who have life-limiting conditions. For the purposes of this review, "healthcare users" will be taken to include children who have life-limiting conditions and their families. The question to be addressed is: What are healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions? BACKGROUND: The prospect of the death of a child from an incurable medical condition is harrowing, yet finding a way to discuss this prospect is crucial to maximize the quality of life for such children and their families. High-quality communication is well recognized as a core skill health care professionals need to maximize the quality of care they provide. This skill is valued by service users, who consistently rate it as one of the highest priorities for the care they receive. Evidence suggests, however, that healthcare professionals can feel ill-equipped or uncomfortable communicating with and about such children. Therefore, it is important to understand what represents high-quality communication and what is involved in accomplishing this within pediatric palliative care. In recent decades there has been an increased focus on providing palliative care for children who have life-limiting conditions. These are conditions for which no cure is available and for which the probable outcome is premature death. Palliative care may also be appropriate for children who have life-threatening conditions; these are conditions where there is not only a high probability of premature death but also a chance of long-term survival into adulthood Although pediatric palliative care is underpinned by the same philosophy as adult palliative care, children who have life-limiting conditions and their families have particular needs that distinguish them from users of adult palliative care. For example, at a physical level children are more likely than adults to have non-malignant conditions that follow trajectories in which children oscillate between feeling relatively well and acutely unwell. The social dynamic of their care is also radically different, particularly given the role of parents or guardians in making surrogate decisions about their child's care. Such factors warrant considering pediatric palliative care as distinct from palliative care more generally. Although the particular circumstances of children who have life-limiting conditions have led to development of pediatric palliative care, the particular provisions of this care differs among countries. One aspect of variation is the age range of patients. Pediatric palliative care is usually provided to neonates, infants, children, adolescents and young adults, but international variations in the definitions of these age ranges, particularly for adolescents and young adults, means pediatric palliative care is provided to different age groups in different countries. This review therefore adopts a pragmatic rather

than an age-based definition of a pediatric palliative care, considering all studies relating to service users who are being cared for by pediatric rather than adult healthcare services. In catering for the unique needs of children who have life-limiting conditions and their families, pediatric palliative care aims to achieve pain and symptom management, enhanced dignity and quality of life, and psychosocial and spiritual care. It also seeks to incorporate care for patients' broader families and facilitating access to appropriate services and support. High-quality communication is crucial for achieving these aims. It enables healthcare users and providers to make decisions that underpin the care that is provided and the quality of the life that is possible for patients and their families.  Although both users and providers recognize the value of high-quality communication with and about children who have life-limiting conditions, this does not mean that these stakeholders necessarily share the same perspective of what constitutes high-quality communication and the best way of accomplishing this. Focusing on healthcare users' experiences of communication with healthcare professionals about children who have life-limiting conditions, the present review will explore the subjective impact of professionals' communication on the people for whom they provide care.It may be necessary to consider a range of contextual factors to understand healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions. For instance, age, developmental stage, cognitive capacity, emotional and social strengths, and family dynamics can influence a child's level of involvement in discussions about their condition and care. Although there are factors that appear more consistent across the range of pediatric palliative care users, such as parents' preferences for being treated by healthcare professionals as partners in making decisions about the care of their child, there is not always such consistency. Nor is it clear whether such findings can be generalized across different cultural contexts. In appraising existing research, this systematic review will therefore consider the relationship between the context of individual studies and their reported findings. The primary aim of this review is to identify, appraise and synthesize existing qualitative evidence of healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions. The review will consider relevant details of these findings, particularly whether factors like age are relevant for understanding particular experiences of communication. An outcome of this review will be the identification of best available qualitative evidence that can be used to inform professional practice, as well as an identification of priorities for future research in pediatric palliative care. A preliminary search in MEDLINE and CINAHL found primary studies exploring healthcare users' experiences of aspects of communicating with healthcare professionals about children who have life-limiting conditions. A search was also conducted for existing systematic reviews in PubMed, CINAHL, EMBASE, PsycINFO, the Cochrane Database of Systematic Reviews, the JBI Database of Systematic Reviews and Implementation Reports, and PROSPERO. No systematic reviews on this topic were found.

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47. **Should Older Teens and Young Adults With Chronic, Life-Threatening Pediatric Illnesses be Transitioned to Adult Providers and Care Based on Chronologic Age?**
**Item Type:** Journal Article
**Authors:** McCarthy, Colleen and McKie-Addy, Cynthia
**Publication Date:** May ,2015
**Journal:** MCN: The American Journal of Maternal Child Nursing 40(3), pp. 142-143
**DOI:** https://libkey.io/10.1097/NMC.0000000000000138

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48. **Characteristics of young people with long term conditions close to transfer to adult health services.**
**Item Type:** Journal Article
**Authors:** Merrick, Hannah; McConachie, Helene Coureur, Ann; Mann, Kay; Parr, Jeremy R.; Pearce, Mark

S.;Colver, Allan and Transition Collaborative Group
**Publication Date:** Sep 30 ,2015
**Journal:** BMC Health Services Research 15, pp. 435
**Abstract:** BACKGROUND: For many young people with long term conditions (LTC), transferring from paediatric to adult health services can be difficult and outcomes are often reported to be poor. We report the characteristics and representativeness of three groups of young people with LTCs as they approach transfer to adult services: those with autism spectrum disorder with additional mental health problems (ASD); cerebral palsy (CP); or diabetes. METHODS: Young people aged 14 years-18 years 11 months with ASD, or those with diabetes were identified from children's services and those with CP from population databases. Questionnaires, completed by the young person and a parent, included the 'Mind the Gap' Scale, the Rotterdam Transition Profile, and the Warwick and Edinburgh Mental Wellbeing Scale. RESULTS: Three hundred seventy four young people joined the study; 118 with ASD, 106 with CP, and 150 with diabetes. Participants had a significant ($p < 0.001$) but not substantial difference in socio-economic status (less deprived) compared to those who declined to take part or did not respond. Condition-specific severity of participants was similar to that of population data. Satisfaction with services was good as the 'gap' scores (the difference between their ideal and current care) reported by parents and young people were small. Parents' satisfaction was significantly lower than their children's ($p < 0.001$). On every domain of the Rotterdam Transition Profile, except for education and employment, significant differences were found between the three groups. A larger proportion of young people with diabetes were in a more independent phase of participation than those with ASD or CP. The wellbeing scores of those with diabetes (median = 53, IQR: 47-58) and CP (median = 53, IQR: 48-60) were similar, and significantly higher than for those with ASD (median = 47, IQR: 41-52; $p < 0.001$). CONCLUSIONS: Having established that our sample of young people with one of three LTCs recruited close to transfer to adult services was representative, we have described aspects of their satisfaction with services, participation and wellbeing, noting similarities and differences by LTC. This information about levels of current functioning is important for subsequent evaluation of the impact of service features on the health and wellbeing of young people with LTCs following transfer from child services to adult services.

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49. **Becoming a back-up carer: Parenting sons with Duchenne muscular dystrophy transitioning into adulthood.**
**Item Type:** Journal Article
**Authors:** Yamaguchi, M. and Suzuki, M.
**Publication Date:** 2015
**Journal:** Neuromuscular Disorders 25(1), pp. 85-93
**Abstract:** The population of adults with Duchenne muscular dystrophy is increasing rapidly. However, information for individuals with DMD and their parents about the transition to adulthood is lacking; young adult sons and their parents may struggle to maintain smooth family functioning and well-being during this period. This study examined the process of change in parental behaviors during their son's transition. The participants were 18 parents with sons aged 15-30 years. Data were obtained from semi-structured interviews and analyzed using a grounded theory approach. Eleven categories of behaviors were identified across three domains: emotional, physical, and determination. The changes made by parents were directed toward becoming a back-up carer: letting go of some control but still being active participants in their sons' lives. We identified several issues important for well-being in the transition period: psychological support, the aging of the parents (the primary caregivers) and the concomitant emergency and specialized care needs, and parents' intervention in the self-determination of adult sons with DMD. The findings of this study may provide a rationale to advocate for policies to

improve support for parents of sons with DMD transitioning to adulthood and provide information to help parents in their role as primary care providers.

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50. **Opening end-of-life discussions: how to introduce Voicing My CHOiCESTM, an advance care planning guide for adolescents and young adults.**
**Item Type:** Journal Article
**Authors:** Zadeh, S.;Pao, M. and Wiener, L.
**Publication Date:** 2015
**Journal:** Palliative & Supportive Care 13(3), pp. 591-599
**Abstract:** OBJECTIVE: Each year, more than 11,000 adolescents and young adults (AYAs), aged 15-34, die from cancer and other life-threatening conditions. In order to facilitate the transition from curative to end-of-life (EoL) care, it is recommended that EoL discussions be routine, begin close to the time of diagnosis, and continue throughout the illness trajectory. However, due largely to discomfort with the topic of EoL and how to approach the conversation, healthcare providers have largely avoided these discussions. METHOD: We conducted a two-phase study through the National Cancer Institute with AYAs living with cancer or pediatric HIV to assess AYA interest in EoL planning and to determine in which aspects of EoL planning AYAs wanted to participate. These results provided insight regarding what EoL concepts were important to AYAs, as well as preferences in terms of content, design, format, and style. The findings from this research led to the development of an age-appropriate advance care planning guide, Voicing My CHOiCESTM. RESULTS: Voicing My CHOiCESTM: An Advanced Care Planning Guide for AYA became available in November 2012. This manuscript provides guidelines on how to introduce and utilize an advance care planning guide for AYAs and discusses potential barriers. SIGNIFICANCE OF RESULTS: Successful use of Voicing My CHOiCESTM will depend on the comfort and skills of the healthcare provider. The present paper is intended to introduce the guide to providers who may utilize it as a resource in their practice, including physicians, nurses, social workers, chaplains, psychiatrists, and psychologists. We suggest guidelines on how to: incorporate EoL planning into the practice setting, identify timepoints at which a patient's goals of care are discussed, and address how to empower the patient and incorporate the family in EoL planning. Recommendations for introducing Voicing My CHOiCESTM and on how to work through each section alongside the patient are provided.

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