

# GLOBAL NEWS SERIES FOR HEMOPHILIA NURSES



January 2008 Issue

## Message from the Editor

Welcome to the Global News Series for Hemophilia Nurses. The purpose of the Global News Series is to share knowledge, experience and current events among hemophilia nurses around the world. The topics for each edition are chosen from suggestions received from readers. Subject matter experts from the global hemophilia community help develop the content as well as ensure the accuracy, applicability and usefulness of the information. To provide feedback, suggestions for topics, or express your interest as a subject matter expert, please e-mail us at [contactus@solutionsight.com](mailto:contactus@solutionsight.com) or write us at SolutionSight, Inc., 2191

Avalon Drive, Buffalo Grove, Illinois 60089. The newsletter is sponsored by an educational grant from Baxter Healthcare Corporation.

This month we will present information about transition in hemophilia. Our goal is to include information from a number of countries related to the process of transition. Due to the variation in approved therapies and practices, we do not provide specific prescriptive recommendations. ❖

Cindy Ping, RN, BSN, MBA, CPP

This Issue's Focus

## Transition in Hemophilia

Transition is a life process that may be physical, psychosocial, moral, spiritual or emotional in nature, temporarily disrupting the normal processes in life and requiring adaptation for the person experiencing it.<sup>1</sup> Transition occurs throughout life for all people, but for those with chronic illness, it takes on additional significance due to the nature of their disease process. In this edition, we will address the specific needs of the person with hemophilia, focusing on the transition between child-centered and adult-centered care. Additional examples of transition for the person with hemophilia are:

- the physical, social and emotional changes a young person experiences as he/she becomes an adolescent;

- switching from central venous access to peripheral access for factor infusions;
- leaving home for advanced education or a career;
- moving from a single life to marriage;
- decisions to become a parent; and
- considerations for aging and retirement.

In this issue we will discuss many aspects of transition and provide tools and resources for you to use with your patients as they make these challenging and rewarding steps toward their future. ❖

*Note: Although hemophilia and male patients are discussed throughout the newsletter, we acknowledge the presence of other bleeding disorders and female patients also. Transition carries the same importance with these considerations.*

## Advisory Board

January 2008

We are pleased to introduce the subject matter experts for this edition of the Global New Series for Hemophilia Nurses: Greta Mulders, RN, Mariejan Scholten, RN, and James Munn, RN, MS. Their knowledge and experience in addressing transition with their patients and patients' families have contributed to the materials in this edition. Greta Mulders is a Hemophilia Nurse Specialist at Erasmus Medical Center located in Rotterdam, The Netherlands. Mariejan Scholten is a Pediatric Hemophilia Consultant and has worked for thirty years with children with hemophilia at Erasmus Medical Center and Sophia Children's Hospital, also in Rotterdam, The Netherlands. James Munn is the Program and Nurse Coordinator at the University of Michigan Hemophilia Treatment Center, Ann Arbor, Michigan, USA.

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# Planning and Guidance

Successful progression through the transition process requires patients, parents/caregivers and healthcare providers work together, identifying goals and strategies for individual plans of action. One goal of transition for the treatment team is “to provide healthcare that is uninterrupted, coordinated, developmentally appropriate and psychologically sound prior to and throughout transfer into the adult system.”<sup>2</sup>

Transition requires adequate preparation and requires long term follow-up in the adult healthcare arena.<sup>3</sup> It must balance the need of the adolescent for privacy, confidentiality and increasing responsibility with the need of the parent/caregiver to provide appropriate support to the young person.<sup>4</sup> When the adult learns to “let go,” the adolescent has the opportunity to become empowered in self-care. Coordination of transition plans and services, directed by the healthcare team, take place among the person with hemophilia, families and other professionals. Planning the transition process leads to measurable outcomes.<sup>4</sup> Consider these points when planning transition services:<sup>4,5</sup>

- Address professional attitudes, helping others realize transition is a process, not a single event.
- Recognize that the medical team at each level of patient care has investments in the person with hemophilia. It can be difficult for the provider to “let go” also.
- Establish on-going communications between the multiple disciplines and facilities that are involved in patient care.
- Create appropriate environments for the patient’s stage of development.
- Consult with and involve young people and their parents/caregivers in the planning and delivery of health services. Needs will vary

based on specific medical, social and cultural circumstances. It’s important that healthcare teams understand these variations to provide optimal guidance and support for the person with hemophilia.

- Develop a process for involving young people in their own care with key milestones. Gradually increase responsible decision-making.
- Allow for flexibility with time of transfer between pediatric and adult care. Age limits or chronological age should not be the only consideration. Cognitive and physical development, emotional maturity and state of health are also considerations for transition.
- Set up educational programs, including transition checklists, for the young person and parents/caregivers to provide knowledge and skills for the change to an adult service.
- Establish on-going educational programs for nursing staff and other healthcare providers/agencies involved in transition policies and healthcare agendas.
- Identify adult care services that are interested and capable to work with those transferring from pediatric services.
- Plan coordinated processes and procedures for transfer from one level of care to another. Strategic plans for care may share expertise, carry out joint assessments and pool resources. Audits to measure satisfaction, response and compliance of patients and families are important.



- Determine a coordinator for the young person’s care, able to integrate the various treatment and management needs. Input from the young person about the coordinator is important and significant.
- Due to the size of medical records, consider options for information transfer. The goal is to share as much information in as simple and concise a format as possible.
- Establish monitoring mechanisms to assure care is being delivered and received when moving from pediatric to adult care settings.
- Ensure primary care providers are involved with the transition to adult care.
- Negotiate administrative support to assist in recordkeeping, information transfer and management of transition policies and procedures.

## Models of Transition<sup>4</sup>

It’s important to understand that transfer of young people from a pediatric to an adult care setting is not the same as the process of transition. There are several models of transition identified by the United Kingdom’s Department of Health, although there is no clear evidence that one is superior. The models include:

- A dedicated follow-up service provided within the adult setting with no direct input or continuity from previous pediatric services - This is the simplest model but, in order to work well, there needs to be coordination and communication between the previous pediatric care and the new adult care components (e.g. pediatric nurse specialists taking young people to the adult clinics and meetings between the pediatric and adult clinic staff to plan coordinated care).

For more resources and suggestions, log on to:  
[www.SolutionSight.com/january2008](http://www.SolutionSight.com/january2008)

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# Transition

# Stages and Milestones

The U.S. National Hemophilia Foundation's Medical and Scientific Advisory Council's (MASAC) Transition Guidelines<sup>6</sup> were developed in response to the challenges of transition for persons with hemophilia, parents/caregivers and Hemophilia Treatment Centers (HTCs). The guidelines are based on age and organized into relevant categories with goals and strategies for each category. The categories addressed in the transition guidelines are social support; health and lifestyles; educational, vocational and financial planning; self-advocacy and self-esteem; independent healthcare behaviors and sexual health. Understanding the different stages and milestones of transition provides the person with hemophilia and parents/caregivers more information to successfully develop individual goals and strategies for transition planning.

The U.S. National Hemophilia Foundation's Medical and Scientific Advisory Council's (MASAC) Transition Guidelines identify the following stages of transition:<sup>6</sup>

- **Birth to Adolescence:** through 12 years old
- **Early Adolescence:** 13-15 years old
- **Late Adolescence:** 16-18 years old
- **Young Adulthood:** 19-22 years old
- **Adulthood:** 22 years old and up

Transition milestones are significant points in development and are used as guidelines, not as rules. Based on age and the stage of transition, each person accomplishes milestones in his own way. The process of reaching

milestones often differs from one individual to another, and will occur at different timeframes. It's important to remember the goal is to learn about life and to achieve independence.

## **Birth to Adolescence Milestones (0-12 years of age)**

Initially, families begin to learn about hemophilia under the direction of a healthcare team that specializes in hemophilia care. Protective safety measures are put in place at home. Together, the child and the family learn about living with hemophilia, providing treatment at home and performing self-infusion. Socialization takes place for the child at the treatment center, in school and at hemophilia camp.

## **Early Adolescence Milestones (13-15 years of age)**

The person with hemophilia begins to consider and put into place a plan and philosophy for life. Talking with parents and treatment center staff, the young person learns to recognize the signs, symptoms and treatment options of bleeds. He becomes more proactive with his own care, takes more responsibility and increases the decision-making of treatment. The value of a healthy diet, exercise and adequate rest are recognized. Socially, friendships develop and participation in more activities takes place. The young

person begins to tackle moral questions and explore puberty and sexual health with families, counselors and treatment teams there for support and guidance. School activities and sports are important as well as educational and vocational opportunities. Steps are taken to begin defining future plans and career interests.

## **Late Adolescence Milestones (16-18 years of age) and Young Adulthood (19-22 years of age)**

As the person with hemophilia matures, he continues to develop a philosophy of life, individuality and friendships; participates in treatment, decision-making, and record keeping; and gains a deeper understanding of hemophilia, one's well-being and sexual health. Greater responsibility is taken for all areas of life, including healthcare decisions; making a stronger commitment to vocation, education and career; starting to think about intimate relationships and considering whether or not to start a family.

## **Adulthood (22 years of age and older)**

Maintaining and managing a healthy lifestyle is one of the goals as an adult. Reaching adulthood is not the end of transition but one more step in the process. As adults, transition includes moving from school to work environments, choosing a life partner and deciding to start a family. Life is interesting and exciting with educated decisions about transition. ❖



## Key Term

**Transition:** A movement, passage, or change from one position, state or stage to another; changes from one life period—physical, psychosocial, moral, spiritual or emotional—to another. Transition temporarily disrupts normal life and requires adaptation.

## Checklist Independence

**Readiness for independence can be measured by responding "YES" to the following checklist:**

- I consistently and promptly identify and treat bleeds.
- I self-infuse at home and away.
- I inventory, store and order my supply of factor.
- I maintain my infusion supplies.
- I complete a log after each infusion.
- I know what type of insurance I have and who provides my factor.
- I make and keep clinic appointments or call to reschedule.
- I come prepared to my treatment center with a list of questions or concerns, as well as having current copies of treatment logs.
- I do home exercises as instructed by my physical therapist.
- I follow the advice of my treatment center and/or healthcare teams.

**As an adolescent/young adult, ask yourself:**

- Do I have a good knowledge of my bleeding disorder and my treatment regimen?
- Do I have the ability to identify an acute bleed?
- Am I taking my factor as prescribed? Who can I call if I have questions about my treatment?
- Do I keep my own records and report any challenges?
- Do I understand my responsibility with diet, exercise, physical therapy, RICE?
- Am I able to have direct interaction with my healthcare team?
- Do I have an understanding of my rights as a patient?
- Do I attend hemophilia camp? Do I wear Medic Alert?

**As an adult with hemophilia, ask yourself:**

- Do I understand my healthcare needs, keep my own records and participate in my treatment and decision-making?
- Can I negotiate decisions, roles and responsibilities for my healthcare?
- Am I planning my future, assessing realistic goals?
- Am I seeking out health care benefits for my life?

## Key Transition From Child to Adult

Modern medicine treats many chronic conditions more and more successfully, leading to an increased life expectancy. Along with increased life expectancy for persons with hemophilia, the possibility of limitations from their chronic disease also exists. Due in part to these challenges, persons with hemophilia will always need to interact with and receive care from a multidisciplinary healthcare team.

Accomplishing an efficient and caring transition for adolescents from pediatric to adult care is one of the greatest challenges facing providers of pediatric healthcare. The adolescent stage can be one of the most difficult with its social, emotional and physical changes. The adolescent is trying to consolidate his identity, achieve independence from parents, establish adult relationships outside the family and find a vocation. Arrangements for transfer into the adult sector are variable, and facilities in both pediatric and adult settings may or may not meet the needs of this age group. The person with hemophilia and his family must continue to grow and develop through life's stages to achieve the transition milestones.

### One Transition Program

One example of a successful program is in Rotterdam, The Netherlands, at Erasmus Medical Center and Sophia Children's Hospital. These institutions have worked together to establish a program for transition from child care to adult care. Sophia Children's Hospital



cares for the person with hemophilia from birth until 16-18 years of age with the focus being on school and social behavior. Parents and caregivers are very involved in the treatment plan. With adult care at Erasmus Medical Center, emphasis is on adherence and treatment of complications. The treatment interaction is primarily between the person with hemophilia and the healthcare team.

The program is structured to focus on transition very early in a child's life. Once a year, an evening of information is offered to parents and grandparents of children with hemophilia, ages 0-8 years old. The entire hemophilia team is present, exchanging experiences, ideas and problems. On this evening, the Kidscamp for young people from 5-11 years of age is introduced. These camps are designed to teach the young people about their hemophilia and initial self-care processes, including administration of factor. The Survival Camp, a program for older youth, continues to increase the young men's knowledge about their bleeding disorder and further

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## Online Resource

A comprehensive transition healthcare checklist and informational packet is available for use by youth, families and professionals moving through transition periods. It is offered on-line by the Department of Health, Pennsylvania, USA for educational purposes at:

[www.health.state.pa.us/transitionchecklist](http://www.health.state.pa.us/transitionchecklist)

A group of checklists for key areas of transition from the Royal College of Nurses, United Kingdom, including behaviors, actions and evidence for the areas of self-advocacy, independent healthcare behavior, sexual health, psychosocial support, educational and vocational planning, and health and lifestyle are available at:

[www.rcn.org.uk](http://www.rcn.org.uk)

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self-care. Healthcare personnel and the camp participants have a good time while learning with lots of planned outdoor activities such as tug-of-wars in the woods, rafting on the river, and activities to build self-confidence and self-esteem. This takes place under leadership of professionals and the hemophilia team. During the first camp, it was discovered the young campers had insufficient knowledge about the clinical aspect of hemophilia care. Additional teaching was initiated regarding anti-coagulants, treatment options, confrontation as related to their condition, and a better understanding of their future opportunities and challenges.

Teaching and learning interactions take place at central locations. The sessions are set-up for inquiries about specific hemophilia issues with multidisciplinary consultations available. Transfer of knowledge is broken down into practical training (from age 10) and theory instruction (from age 15). Following theory instruction, the camper takes an examination and is awarded a certificate for his achievement.

Once a year, there is a special Transition Day for young men from 13-17 years of age from the Children's Hospital and from 17-21 years of age from the adult hospital. The hemophilia teams of both hospitals organize the day, and then work together on a theme. Following educational sessions, the young people take part in the Survival Camp which includes physical activities like snowboarding or survival skills. One of the important things about this day is the introduction of the young people to the hemophilia team of the adult care center.

At about 18 to 19, patients have their last appointment in the children's



hospital. It's important that the young person and his parents, together with the doctor and the nurse, decide when they will transition to the adult care center. Transition to adult care involves a medical transfer, doctor's referral and a new consultant to manage the youth's care in the adult center. The adult care center nurse meets the patient, the family and the child care center nurse half-way across a bridge between the two centers, and there she takes the family with her to the adult center. The bridge is symbolic of the bridge of transition between the two stages. The first appointment is spent getting acquainted with doctors and nursing staff in the new facility. The goal is to encourage independence of the young person from his parents. The follow-up program for home care includes a transition book.

Some of the challenges of the program include the development of confidential relationships, cultural differences in the patient groups, different methods of treatment, as well as anxiety and uncertainty among the learners. The young people are required to be aware of their health condition and are responsible for their treatment, medications, making their own appointments and notifying the health-care team of symptoms of bleeds.

The program's success is due to cooperation between Sophia Children's Hospital and Erasmus Medical Center, development and interaction of multidisciplinary treatment teams, more individualized timing of transition, theory examinations for transition, hemophilia games, national contacts, follow-up home care, development of a checklist for patient's use and a transition book entitled "Over the Bridge". ❖

## By Mariejan Scholten "Over the Bridge"

As the hemophilia consultant at Erasmus Medical Center/Sophia Children's Hospital in Rotterdam, I wanted to develop a book about transition for young people with hemophilia and their parents. It started as a cooperative effort between the nurses of the two hospitals.

There were two reasons I felt this book needed to be developed. Transition used to consist of a letter from the doctor and a telephone



number for the family to call at the adult care center. That was transition! Patients and families felt lost and had difficulty moving from the pediatric care center to

the adult care center and treatment. Secondly, there was a lack of knowledge about the condition of hemophilia with patients and families.

Transition to an adult care center is explained step-by-step, helping the hemophilia patient take responsibility for his illness as it shifts from his parents. We initiated a research project between the Children's Hospital and the High School of Rotterdam in order to create a better plan for transition. The project included presentations and projects which are discussed in the book.

Currently used in the Netherlands, this material seems to be very helpful in the process of transition. The methods we used are discussed and can be applied in any hemophilia center. Other people with chronic illnesses may also find the book's information very helpful.

## Transition Program Spanning a Lifetime

The University of Michigan (U.S.) strives to provide care along the life continuum that is uninterrupted and a smooth process for the youth, family and staff. Because it is a “lifespan” program (following the patients from cradle to rocking chair), this process is achieved with minimal disruption to all involved. The program has a distinction among other chronic disease clinics at the University for having a streamlined process with respect to transitioning. Because bleeding disorders are congenital, multiple family members in various genera-

tions can be affected. For this reason, clinics are offered for adults and children on the same day. By doing this, young patients become familiar with the adult physician and what the program has to offer them as they mature into adulthood. Often, the younger patients start questioning the adult physician before they make their official “first visit” in the adult clinic. Parents are relieved to know the majority of the healthcare team works both clinics – except the physicians. The staff knows the child and their individual needs from the day they are diagnosed to the day they decide to leave the program.

Keeping anxiety down during life transitions can be helpful to the individual mastering the step from one stage to the next. Using transition guidelines from an early age with coordinated components, decreases fear of the unknown and prepares everyone for the steps that face each young person as they grow. It’s important to realize that there are resources that have been developed and are in use to help with this process. Materials are being created for the transition periods in adult patients, too – making sure that changing needs are

addressed proactively if possible, and with a comprehensive team approach.



For more resources, log on to:  
[www.SolutionSight.com/january2008](http://www.SolutionSight.com/january2008)

## Transition “Letting Go”

“Letting go” through transition can be very challenging for parents. They may fear losing control in their child’s life, which can be particularly difficult when that child has chronic medical needs. Parents are anxious and uncertain about new situations for their child as the familiar relationships change. They feel responsible for reporting problems and complications, always having been involved in making decisions.

When their child gets older, their role will be totally different. Parents of teens run the gamut of emotions as well. Learning to let go is perhaps the most difficult—but also the most necessary—task of all. Independence for the child is easier with the parents’ encouragement, even if they are hesitant and unsure of the final outcomes. It’s important that the parents have confidence in the independence and responsibility of their child as well as with any new healthcare setting. Without letting go, the young person with hemophilia will be delayed in moving forward with potentially negative consequences. By learning to let go, the parent will help the child develop new and secure relationships with the healthcare team and the outside world, enhancing self-reliance and self-esteem as well as good medical care.

According to the American Academy of Child and Adolescent Psychiatry, teenagers with lifelong diseases face unique psychological challenges: “A teenager with a long-term illness may feel pulled in opposite directions. On the one hand, he or she must take care of the physical problem, requiring dependence on parents and doctors. On the other

hand, the adolescent wants to become independent and join his or her friends in various activities.”<sup>17</sup> To move from protector to ally, parents/caregivers must ask themselves:

- Can I help my child learn how to be his own advocate?
- Can I give my child room to make decisions and mistakes?
- Can I support my child’s choices, but not step in to do it for him?



Parents/caregivers and treatment centers can help young adults achieve readiness for independence in many ways, such as: give praise, set limits, promote self-infusion and support hemophilia

camp. They can also facilitate transition to adult care by promoting:

- **Courage:** to move to a new phase of life
- **Independence:** to speak up when you have needs
- **Confidence:** to make choices and develop who you are
- **Responsibility:** to attend comprehensive clinics and actively participate in your care

The treatment center and healthcare team help the young person through transition also. At appointments, the focus is more on individual time with the child/adolescent and less with the parent/caregiver. Training for home and self-infusion provides stepping stones for transition. The treatment center encourages independence by transferring more responsibility to the young adult. Both parents and treatment team can facilitate the process of letting go through their encouragement and support of the person with hemophilia. ❖

## Online Resource

The Parent Empowerment Newsletter (PEN) published by LA Kelley Communications, Inc. is filled with great information for parents about hemophilia. It is available in hard copy or electronically and is free to patients, families, hospitals, non-profit organizations and corporate partners at:

[www.kelleycom.com/archives.html](http://www.kelleycom.com/archives.html)

# Transition Online Resources

## [www.kelleycom.com/archives.html](http://www.kelleycom.com/archives.html)

Chronic medical disorders like hemophilia can present such challenges. Parents feel overwhelmed because they often lack the educational tools needed. LA Kelley Communications was founded on the belief that anyone facing hardship, adversity or challenges—when given the right tools—can overcome, triumph, and even grow in character and confidence. Find out more about The Parent Empowerment Newsletter (PEN) published by LA Kelley Communications, Inc. Filled with great information for parents, it is available in hard copy or electronically. It is free to patients, families, hospitals, non-profit organizations and corporate partners.

## [www.hemophiliagalaxy.com](http://www.hemophiliagalaxy.com)

Hemophilia Galaxy website is sponsored by Baxter BioScience. This website links the reader to a vast amount of information about hemophilia and its management, stages of growth and development as related to the condition, community resources, healthy decision with hemophilia, health insurance information and many resources. Hemophilia toolkits for persons with hemophilia and family are also described with directions for acquiring them.

## [www.livingwithhaemophilia.com](http://www.livingwithhaemophilia.com)

Living with Hemophilia website is sponsored by Bayer. This website has lots of information about living with the condition of hemophilia, including a special section on Transition. Specific guidance is also addressed about issues at home and on the go. Guest contributors offer experience and support for families of hemophilia.

## [www.hemophiliavillage.com](http://www.hemophiliavillage.com)

Wyeth sponsors the Hemophilia Village website. It provides information about hemophilia and its treatment as well as programs and services available to the hemophilia community. Materials specifically focused on transition to college and higher education is available.

A complete listing along with website descriptions of these additional resources can be found at:  
[www.SolutionSight.com/january2008](http://www.SolutionSight.com/january2008)

## **Self Advocacy/Encouraging Independent Health Behavior**

[www.savethechildren.org.uk/rightonline](http://www.savethechildren.org.uk/rightonline)  
[www.after16.org.uk](http://www.after16.org.uk)

## **Sexual Health**

[www.brook.org.uk](http://www.brook.org.uk)  
[www.fpa.org.uk](http://www.fpa.org.uk)  
[www.mariestopes.org.uk](http://www.mariestopes.org.uk)  
[www.likeitis.org.uk](http://www.likeitis.org.uk)

## **Psychological Support**

[www.youngminds.org.uk](http://www.youngminds.org.uk)  
[www.childline.co.uk](http://www.childline.co.uk)

## **Educational and Vocational Planning**

[www.connexions.gov.uk](http://www.connexions.gov.uk)  
[www.after16.org.uk](http://www.after16.org.uk)  
[www.skill.org.uk](http://www.skill.org.uk)

## **Health and Lifestyle**

[www.lifebytes.gov.uk](http://www.lifebytes.gov.uk)  
[www.mindbodysoul.gov.uk](http://www.mindbodysoul.gov.uk)  
[www.teenagehealthfreak.com](http://www.teenagehealthfreak.com)

## **General Transition Websites**

<http://depts.washington.edu/healthtr>  
[www.chfs.ky.gov/ccshcn/ccshcntransition.htm](http://www.chfs.ky.gov/ccshcn/ccshcntransition.htm)  
<http://hctransitions.ichp.edu/>  
[www.dh.gov.uk/childrensnfs](http://www.dh.gov.uk/childrensnfs)  
[www.everychildmatters.gov.uk/deliveringinservices/leadprofessional](http://www.everychildmatters.gov.uk/deliveringinservices/leadprofessional)  
[www.rcn.org.uk](http://www.rcn.org.uk)  
[www.rcpch.ac.uk](http://www.rcpch.ac.uk)  
[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)  
[www.socialexclusion.gov.uk](http://www.socialexclusion.gov.uk)  
[www.bcchildrens.ca/default.htm](http://www.bcchildrens.ca/default.htm)  
[www.rch.org.au/transition](http://www.rch.org.au/transition)  
[www.health.vic.gov.au/subacute/transfer\\_young.pdf](http://www.health.vic.gov.au/subacute/transfer_young.pdf)  
[www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)  
[www.transitionpathway.co.uk](http://www.transitionpathway.co.uk)  
[www.dreamteam-uk.org](http://www.dreamteam-uk.org)  
[www.dipex.org](http://www.dipex.org)

## **Health-related Sites for Young People**

[www.youthhealthtalk.org](http://www.youthhealthtalk.org)  
[www.teenagehealthfreak.org](http://www.teenagehealthfreak.org)  
[www.archdischild.com](http://www.archdischild.com)  
[www.health.state.pa.us/transitionchecklist](http://www.health.state.pa.us/transitionchecklist)

## **Hemophilia Resources**

[www.hemophilia.org](http://www.hemophilia.org)  
[www.hemophiliafed.org](http://www.hemophiliafed.org)  
[www.hemophilia.ca](http://www.hemophilia.ca)  
[www.wfh.org](http://www.wfh.org)  
[www.ineedpsi.org/psip.cfm](http://www.ineedpsi.org/psip.cfm)  
[www.cdc.gov/ncbddd/hbd/hemophilia.htm](http://www.cdc.gov/ncbddd/hbd/hemophilia.htm)  
[www.fda.gov/cber/index.html](http://www.fda.gov/cber/index.html)  
[www.aabb.org](http://www.aabb.org)  
[www.patientnotificationsystem.org](http://www.patientnotificationsystem.org)  
[www.nlm.nih.gov/medlineplus/hemophilia.html](http://www.nlm.nih.gov/medlineplus/hemophilia.html)

## **Hepatitis Resources**

[www.liverfoundation.org](http://www.liverfoundation.org)  
[www.hepfi.org](http://www.hepfi.org)  
[www.cdc.gov/ncidod/diseases/hepatitis](http://www.cdc.gov/ncidod/diseases/hepatitis)  
[www.nationalhepatitis-c.org](http://www.nationalhepatitis-c.org)  
[www.hepcassoc.org](http://www.hepcassoc.org)  
[www.all-about-hepatitisc.org](http://www.all-about-hepatitisc.org)  
[www.hepatitis.va.gov](http://www.hepatitis.va.gov)  
[www.frontline-hepatitis-awareness.com](http://www.frontline-hepatitis-awareness.com)  
[www.hcadvocate.org](http://www.hcadvocate.org)  
[www.lola-national.org](http://www.lola-national.org)

## **Arthritis Resources**

[www.arthritis.org](http://www.arthritis.org)  
[www.niams.nih.gov](http://www.niams.nih.gov)  
[www.boneandjointdecade.org/usa](http://www.boneandjointdecade.org/usa)  
[www.cdc.gov/ncddphp/arthritis](http://www.cdc.gov/ncddphp/arthritis)  
[www.arthritis.ca](http://www.arthritis.ca)  
<http://arthritis-research.com>

## **Dental Resources**

[www.dentalhealthfoundation.org](http://www.dentalhealthfoundation.org)  
[www.dentalhealth.org.uk](http://www.dentalhealth.org.uk)  
[www.dentalhealth.ie/dentalhealth](http://www.dentalhealth.ie/dentalhealth)

For a complete listing along with descriptions, log on to:

[www.SolutionSight.com/january2008](http://www.SolutionSight.com/january2008)

## Upcoming Events Conferences

23 – 26 April 2008

**XX Congreso Internacional del Grupo CLAHT – VIII Congreso Argentino del Grupo CAHT**  
(Grupo Cooperativo Latinoamericano de Hemostasia y Trombosis)  
(Grupo Cooperativo Argentino de Hemostasia y Trombosis)  
Buenos Aires, Argentina  
Email: grupoclaht@gmail.com  
www.congresoclaht-caht2008.com

7 – 10 May 2008

**American Pain Society**  
Tampa, Florida, USA  
www.ampainsoc.org

1 – 5 June 2008

**Hemophilia 2008 World Congress**  
Istanbul, Turkey  
E-mail: msalas@wfh.org  
www.hemophilia2008.org

2 – 5 July 2008

**54<sup>th</sup> Annual SSC Meeting of the ISTH**  
Vienna, Austria  
Email: headquarters@isth.org  
www.med.unc.edu/isth/ssc2008

3 – 6 September 2008

**American Society of Pain Management Nursing**  
Tucson, Arizona, USA  
www.aspmn.org/Conference/index.htm

13 – 15 November 2008

**60<sup>th</sup> Annual National Hemophilia Foundation Meeting**  
Denver, Colorado, USA

## Transition Planning (continued from page 2)

- A “seamless” clinic which begins in childhood or adolescence and continues into adulthood, with both child and adult professionals providing ongoing care as appropriate - This joint approach allows patients to benefit from experts in pediatric and adult diseases/healthcare issues. It also allows both groups of specialists to continue to learn from each other and from the patient’s experiences. The duration of joint care should vary from patient to patient and between specialties.
- Life-long follow-up within the pediatric setting - This may happen by default, but may make it more difficult for the young person to access expertise on issues such as contraception, fertility problems, diseases of ageing, or on vocational and benefits issues. It is also more challenging to develop appropriate independent living alongside their peers.
- A generic “transition team” within a children’s hospital – An example is the model developed by the “On Trac” team at British Columbia Children’s Hospital, Vancouver, Canada. It involves having 1-2 dedicated nurse specialists who can ensure that all young people go through appropriate transitions complemented with excellent literature and diaries the Canadian team has developed.
- Generic “transition coordinators” for larger geographical regions – Recently developed by the Department of Health in New South Wales, Australia, the coordinators cover a wider area. This model may be appropriate for conditions which are relatively rare, or for coordinating links between children’s hospitals and local general hospitals. ❖

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