



# Young Adults with Chronic Conditions

## Optimizing Treatment and Transition from Pediatric to Adult Care

March 4–6, 2019 | Cambridge, MA



- New management approaches for chronic conditions in adolescents and young adults
- Tools for assessment of transition readiness and self-management
- Transition timing and timelines, checklists and resources
- Best practices for communication and goal setting with patients and families
- Multidisciplinary care coordination and integration
- Evidence-based quality improvement strategies
- Legal and financial supportive decision-making for patients
- Practice redesign and team-based care
- Updates for sexuality and fertility with chronic disease

Education for:  
PHYSICIANS, NPs, and PAs in:  
Pediatrics  
Internal Medicine  
Family Medicine  
Medicine-Pediatrics  
Pediatric Subspecialties  
Medical Specialties and  
Subspecialties

...and **Psychologists, Social Workers,**  
and **Counselors** who support young  
adults with chronic conditions  
and their families



Register at [TCC.HMSCME.com](https://TCC.HMSCME.com)





# HARVARD MEDICAL SCHOOL

Dear Colleague,

Anyone practicing in primary or subspecialty care recognizes that more adolescents and young adults with chronic conditions of childhood origin are surviving and transitioning into adulthood. The question we then face is: *how can I optimize this transition and ensure the highest levels of care?*

**Consider the following clinical questions:**

- What should I screen for in a cancer survivor?
- How do I reduce cardiovascular risk in my young adult patients?
- How do I best approach a patient with autism?
- What are the state-of-the-art approaches to chronic pain?
- How do I talk about sexuality with my patients?

**Equally important are questions raised by patients about:**

- Independent living
- Self-management
- Self-advocacy
- Decision-making
- Information sharing
- Effective communications

**And many of us have process questions, including:**

- When (and how) should I think about integrating young adults into my practice?
- What are the best ways to prepare patients for adult care?
- How can we more effectively utilize team-based care to optimize the transition?

These frequently asked questions have given rise to an overwhelming demand for evidence-based practices that have been shown to optimize both the transition of care and patient outcomes.

That is precisely what is offered at *Young Adults with Chronic Conditions: Optimizing Treatment and Transition from Pediatric to Adult Care*. Taught by many of the country's most experienced experts, this immersive program provides state-of-the-art strategies, best practices and take-home tools to help you effectively and efficiently transition patients and elevate their quality of life.

If you provide care for or are preparing to accept pediatric patients who are transferring to adult care, this course will prove invaluable. It will inform, update, and inspire you, and you will return to your practice empowered to be a more effective clinician in the care of these patients.

We hope you will join us, and look forward to seeing you in Boston in March!

Sincerely,

**Niraj Sharma, MD, MPH**  
Course Director



# Program Highlights

## Clinical Updates

State-of-the-art approaches to chronic diseases in adolescents and young adults:

- Arthritis
- Autism
- Cancer Survivorship
- Cerebral Palsy
- Congenital Heart Disease
- Cystic Fibrosis
- Diabetes
- Down Syndrome
- Epilepsy
- HIV/AIDS
- Inflammatory Bowel Disease
- Intellectual Disability
- Spina Bifida
- Solid Organ Transplant
- Sickle Cell Disease

Includes:

- Updates and best practices for the management of chronic pain
- Substance abuse: best practices for diagnosis and management
- New strategies for palliative care
- Expanded options for cardiovascular risk reduction in chronic disease

## Family Medicine and Medicine-Pediatric Practices

- Encouraging adherence through shared decision-making: when, why, how
- Differentiating treatment as patients age
- How to effectively teach self-management skills
- Current approaches to preventative counseling and anticipatory guidance

## Pediatric Practices: Strategies and Best Practices to Successfully Transition Young Adults to Adult Care

- Transition timing and tracking of progress
- Assessing functional capacity to determine need for guardianship
- Developing individualized transition plans
- Devising and implementing effective transition policies

## Internal Medicine Practices: Strategies and Best Practices to Successfully Onboard Young Adults into Your Practice

- Understanding unique needs of patients with pediatric acquired illness
- Quality improvement strategies to optimize care of young adults
- Updates to prevent gaps in care as patients move to adult care
- Accommodating the needs of young adults with developmental disabilities in your clinical setting

## Pediatric Subspecialty Practices

- Screening for high-risk behaviors and their impact on chronic illness
- Educating patients about impact of chronic illness on future fertility and pregnancy risks
- Best practices for transition timing: start early and track progress
- Referring to adult primary care providers as medical home for young adults

## Adult Subspecialty Practices

- Encouraging adherence to optimize health outcomes
- Addressing sexual health and fertility issues
- Utilizing shared decision-making to set goals with patients
- Accommodating the needs of young adults with developmental disabilities in your clinical setting

## Preparing Patients and Families for Transition

- Patient advocacy: best practices for educating patients and families to advocate for themselves with:
  - Medical providers
  - Insurance companies
- Strategies for success with the transition to college and community living
- Guidance to build transition curricula

## Process Innovation and Practice Improvement

- Techniques to address social determinants of health in chronic disease management
- State-of-the-art approaches to practice redesign and team-based care
- Advocacy and healthcare reform in transition care
- Involvement of community health care workers in chronic disease management

Includes Take-Home Resources

# Young Adults with Chronic Conditions: Optimizing Treatment and Transition from Pediatric to Adult Care

## Learning Objectives

Upon completion of this course, adult and pediatric providers will be able to:

**Provide state-of-the-art care of chronic childhood conditions in adolescent and adult patients:**

- Single-system disease, including congenital heart disease and epilepsy
- Multisystem disease, including cystic fibrosis and epilepsy
- Intellectual/developmental disabilities, including Down syndrome and autism

**Develop and implement practical strategies to successfully transfer and accept patients with chronic childhood conditions:**

- Care coordination and integration
- Supported decision-making
- Practice redesign and team-based care
- Adolescent health and wellness

**Better navigate healthcare systems and their impact on transition to adult care:**

- Quality improvement
- Reimbursement strategies
- National health policy
- Advocacy

**Enhance your approach to patient and family engagement in chronic condition management and help them to achieve health equity:**

- Communication skills
- Assessing self-management skills and readiness for transition to adult healthcare settings
- Coping with chronic illness
- Supports for community living

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## Course Directors

**Niraj Sharma, MD, MPH**

Assistant Professor of Medicine and Pediatrics  
Harvard Medical School  
Director, Internal Medicine-Pediatrics Unit  
Brigham and Women's Hospital  
Program Director, Harvard Medicine-Pediatrics Residency  
Brigham and Women's and Boston Children's Hospitals

**Kitty O'Hare, MD**

Assistant Professor of Medicine and Pediatrics  
Harvard Medical School  
Medical Director of Pediatric Population Health  
Primary Care Center of Excellence  
Brigham and Women's Hospital  
Director of Transition Medicine for Primary Care  
Weitzman Family BRIDGES Adult Transition Program  
Boston Children's Hospital

**Elizabeth Petersen, MD, MPH**

Instructor in Medicine, Part-time, Harvard Medical School  
Hospitalist Medicine Unit, Brigham and Women's Hospital  
Children's Hospital Inpatient Services,  
Boston Children's Hospital

**Susan Shanske, LICSW**

Director of Transitional Care Support  
Weitzman Family BRIDGES Adult Transition Program  
Department of Medicine, Boston Children's Hospital

## Harvard Medical School Faculty

Maureen M. Achebe, MD  
Richard C. Antonelli, MD, MS  
Ann Marie R. Bergin, MB, ScM, MRCP (UK)  
Rachael B. Coakley, PhD  
Carlos R. Estrada Jr., MD, MBA  
Sarah N. Flier, MD  
Katharine Garvey, MD, MPH  
Laurie J. Glader, MD  
Susan H. Gray, MD  
Scott E. Hadland, MD, MPH, MS  
Jonathan S. Hausmann, MD  
Maureen M. Jonas, MD  
Emma M. Jones, MD  
Kristine D. McKenna, PhD  
Maurice W. Melchiono, RN, MS, FNP-BC, NE-BC  
Colleen A. Monaghan, MD  
Anne M. Neilan, MD, MPH  
Judith S. Palfrey, MD  
Ann H. Partridge, MD, MPH  
Jennifer Turek Queally, PhD  
Stephanie L. Santoro, MD  
Gregory S. Sawicki, MD, MPH  
Alison D. Schonwald, MD  
Keri M. Shafer, MD, FACC  
Sarah J. Spence, MD, PhD  
Lori W. Tishler, MD, MPH  
Ahmet Z. Uluer, DO, MPH

### HARVARD-AFFILIATED FACULTY

Janis H. Arnold, MSW, LICSW  
Lynne Helfand, MSW, MPH, LICSW  
Stacy B. Klickstein, MSW, LICSW  
Julia C. Roboff-Rooney, MSN, FNP-BC, CPN  
Christopher Ryan, MSW, LCSW  
Aubry Threlkeld, EdD

# Agenda

## Accreditation

### ACCREDITATION COUNCIL FOR CONTINUING MEDICAL EDUCATION

The Harvard Medical School is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The Harvard Medical School designates this live activity for a maximum of 25.00 *AMA PRA Category 1 Credits*<sup>™</sup>. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

### AMERICAN BOARD OF INTERNAL MEDICINE

Successful completion of this CME activity, which includes participation in the evaluation component, enables the participant to earn up to 25.00 Medical Knowledge MOC points in the American Board of Internal Medicine's (ABIM) Maintenance of Certification (MOC) program. Participants will earn MOC points equivalent to the amount of CME credits claimed for the activity. It is the CME activity provider's responsibility to submit participant completion information to ACCME for the purpose of granting ABIM MOC points.

### AMERICAN BOARD OF PEDIATRICS

Successful completion of this CME activity, which includes participation in the activity including individual assessments by the participant and feedback to the participant, enables the participant to earn 25.00 MOC points in the American Board of Pediatrics' (ABP) Maintenance of Certification (MOC) program.

### AMERICAN ACADEMY OF FAMILY PHYSICIANS

This Live activity, Young Adults with Chronic Conditions: Optimizing Treatment and Transition from Pediatric to Adult Care, with a beginning date of 03/04/2019, has been reviewed and is acceptable for up to 24.00 Prescribed credit(s) by the American Academy of Family Physicians. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

### RISK MANAGEMENT

This activity meets the criteria of the Massachusetts Board of Registration in Medicine for 1.25 credits of Risk Management Study. Please check your individual state licensing board requirements before claiming these credits.

### PSYCHOLOGISTS

This program will be submitted for continuing education credit. Please see website for updates.

### NURSE PRACTITIONERS and REGISTERED NURSES

For the purpose of recertification, the American Academy of Nurse Practitioners Certification Board and American Nurses Credentialing Center accept *AMA PRA Category 1 Credit*<sup>™</sup> issued by organizations accredited by the ACCME (Accreditation Council for Continuing Medical Education). We would also suggest that learners check with their state licensing board to ensure they accept reciprocity with *AMA PRA Category 1 Credit*<sup>™</sup> for re-licensure.

### PHYSICIAN ASSISTANTS

The National Commission on Certification of Physician Assistants (NCCPA) states that *AMA PRA Category 1 Credits*<sup>™</sup> are acceptable for continuing medical education requirements for recertification. We would also suggest that learners check with their state licensing board to ensure they accept reciprocity with *AMA PRA Category 1 Credit*<sup>™</sup> for re-licensure.

### CANADIAN ACCREDITATION

The Royal College of Physicians and Surgeons of Canada recognizes conferences and workshops held outside of Canada that are developed by a university, academy, hospital, specialty society or college as accredited group learning activities.

### EUROPEAN ACCREDITATION

Through an agreement between the American Medical Association and the European Union of Medical Specialists, physicians may convert *AMA PRA Category 1 Credit*<sup>™</sup> to an equivalent number of European CME Credits<sup>®</sup> (ECMECs<sup>®</sup>). Information on the process of converting *AMA PRA Category 1 Credits*<sup>™</sup> to ECMECs<sup>®</sup> can be found at: [www.eaccme.eu](http://www.eaccme.eu).

## Monday, March 4

7:00 am	<b>Registration and Continental Breakfast</b>
7:30 am	<b>Welcome Remarks: Leaving Neverland</b> Niraj Sharma, MD, MPH and Kitty O'Hare, MD
8:30 am	<b>Congenital Heart Disease</b> Keri M. Shafer, MD, FACC
9:00 am	<b>Diabetes</b> Katharine Garvey, MD, MPH
9:30 am	<b>HIV</b> Anne M. Neilan, MD, MPH
10:00 am	<b>Q&amp;A</b>
10:05 am	<i>Coffee Break (Refreshments provided)</i>
10:20 am	<b>Expert Panel: Transition Readiness and Self-Management in Chronic Disease</b> Gregory S. Sawicki, MD, MPH, Katharine Garvey, MD, MPH, Ahmet Z. Uluer, DO, MPH, Keri M. Shafer, MD, FACC, and Sarah N. Flier, MD
11:00 am	<b>Patient Presentation: Surviving College with Inflammatory Bowel Disease – Patient and Provider Perspectives</b> Janis H. Arnold, MSW, LICSW and Sarah N. Flier, MD
12:00 pm	<i>Break for Lunch*</i>
1:00 pm	<b>Sexuality and Reproductive Health</b> Susan H. Gray, MD
2:00 pm	<b>Workshops A1-A3: Assessing Your Current Practice of Transition Care</b>  <b>Choose one of the following practice areas:</b> <b>A1. Primary Care Practice</b> Kitty O'Hare, MD and Colleen A. Monaghan, MD <b>A2. Specialty Care Practice</b> Ahmet Z. Uluer, DO, MPH and Susan Shanske, LICSW <b>A3. Hospital Medicine</b> Niraj Sharma, MD, MPH and Elizabeth Petersen, MD, MPH
3:00 pm	<b>Q&amp;A</b>
3:05 pm	<i>Coffee Break (Refreshments provided)</i>
3:20 pm	<b>Interest Group Breakouts B1-B3</b>  <b>Choose one of the following:</b> <b>B1. Adolescent Confidentiality</b> Maurice W. Melchiono, RN, MS, FNP-BC, NE-BC <b>B2. Tools to Support Self-Management</b> Kristine D. McKenna, PhD and Lynne Helfand, MSW, MPH, LICSW <b>B3. Fertility and Chronic Disease</b> Julia C. Roboff-Rooney, MSN, FNP-BC, CPN
4:00 pm	<b>Enhanced Communication between Patients and Providers</b>
4:30 pm	<b>Negotiating the Patient/Provider Relationship around Transitions in Care</b> Susan Shanske, LICSW
5:00 pm	<b>Workshop: Writing a Transition Policy Statement</b> Course Directors
6:00 pm	<b>Daily Program Ends</b>

# Agenda

## Tuesday, March 5

7:00 am	<b>Continental Breakfast</b>
7:30 am	<b>Welcome Remarks: Assessing Developmental Progression</b> Susan Shanske, LICSW
8:00 am	<b>Spina Bifida</b> Carlos R. Estrada Jr., MD, MBA
8:30 am	<b>Epilepsy</b> Ann Marie R. Bergin, MB, ScM, MRCP (UK)
9:00 am	<b>Down Syndrome</b> Stephanie L. Santoro, MD
9:30 am	<b>Autism</b> Sarah J. Spence, MD, PhD
10:00 am	<b>Q&amp;A</b>
10:05 am	<i>Coffee Break (Refreshments provided)</i>
10:20 am	<b>Expert Panel: Supported Decision-Making — From Healthcare Proxies to Guardianship</b> Jennifer Turek Queally, PhD, Susan Shanske, LICSW, and Christopher Ryan, MSW, LCSW
11:00 am	<b>Patient Presentation: Community Living for Young Adults with Cerebral Palsy</b> Laurie J. Glader, MD
12:00 pm	<i>Break for lunch*</i>
1:00 pm	<b>Implementing an Integrated Care, Hybrid Transition Model for Youth and Adults with Complex Needs: Early Experience</b> Richard C. Antonelli, MD, MS
2:00 pm	<b>Workshops C1-C3: Incorporating Adults with ID/DD into Your Practice Setting</b>  <b>Choose one of the following practice areas:</b> <b>C1. Primary Care Practice</b> Kitty O'Hare, MD and Colleen A. Monaghan, MD <b>C2. Specialty Care Practice</b> Ahmet Z. Uluer, DO, MPH <b>C3. Hospital Medicine</b> Elizabeth Petersen, MD, MPH
3:00 pm	<b>Q&amp;A</b>
3:05 pm	<i>Coffee Break (Refreshments provided)</i>
3:20 pm	<b>Interest Group Breakouts D1-D3</b>  <b>Choose one of the following:</b> <b>D1. Billing and Coding for Transition Care</b> Colleen A. Monaghan, MD and Niraj Sharma, MD, MPH <b>D2. Educational Advocacy for Youth with ID/DD</b> Alison D. Schonwald, MD <b>D3. Medical Education/Building Transition Curricula</b> Niraj Sharma, MD, MPH and Kitty O'Hare, MD
4:00 pm	<b>Healthcare Reform</b> Niraj Sharma, MD, MPH
5:00 pm	<b>Daily Program Ends</b>

\*There are many convenient and varied lunch options within a short walking distance of the course.

Program changes/substitutions may be made without notice. To view the most up-to-date version of the course program, please visit the course website.

## Wednesday, March 6

7:00 am	<b>Continental Breakfast</b>
7:30 am	<b>Welcome Remarks: Quadruple Aim Approach to Transition Care</b> Ahmet Z. Uluer, DO, MPH
8:00 am	<b>Cancer Survivorship</b> Ann H. Partridge, MD, MPH
8:30 am	<b>Arthritis</b> Jonathan S. Hausmann, MD
9:00 am	<b>Sickle Cell Disease</b> Maureen M. Achebe, MD
9:30 am	<b>Cystic Fibrosis</b> Ahmet Z. Uluer, DO, MPH
10:00 am	<b>Q&amp;A</b>
10:05 am	<i>Coffee Break (Refreshments provided)</i>
10:20 am	<b>Patient Presentation: Impact of Social Determinants of Health on Youth with Chronic Conditions</b> Colleen A. Monaghan, MD and Stacy B. Klickstein, MSW, LICSW
11:20 am	<b>Expert Panel: Chronic Pain and Palliative Care</b> Emma M. Jones, MD and Rachael B. Coakley, PhD
12:00 pm	<i>Break for lunch*</i>
1:00 pm	<b>Solid Organ Transplant</b> Maureen M. Jonas, MD
1:30 pm	<b>Substance Use Disorder</b> Scott E. Hadland, MD, MPH, MS
2:00 pm	<b>Workshops E1-E3: Quality Improvement Strategies to Improve Transition Care</b>  <b>Choose one of the following practice areas:</b> <b>E1. Primary Care Practice</b> Kitty O'Hare, MD and Colleen A. Monaghan, MD <b>E2. Specialty Care Practice</b> Ahmet Z. Uluer, DO, MPH and Susan Shanske, LICSW <b>E3. Hospital Medicine</b> Niraj Sharma, MD, MPH and Elizabeth Petersen, MD, MPH
3:00 pm	<b>Q&amp;A</b>
3:05 pm	<i>Coffee Break (Refreshments provided)</i>
3:20 pm	<b>Interest Group Breakouts F1-F3</b>  <b>Choose one of the following:</b> <b>F1. Cardiovascular Risk Reduction in Young Adults</b> <b>F2. Building a Transition Consultation Program</b> Ahmet Z. Uluer, DO, MPH <b>F3. Community Health Workers to Support Young Adult Health</b> Judith S. Palfrey, MD, and Aubry Threlkeld, EdD
4:00 pm	<b>Innovative Strategies for Chronic Disease Management</b> Lori W. Tishler, MD, MPH
4:30 pm	<b>Final Comments/Wrap-Up</b> Niraj Sharma, MD, MPH and Kitty O'Hare, MD
5:00 pm	<b>Course Adjourns</b>





**HARVARD**  
MEDICAL SCHOOL

# Young Adults with Chronic Conditions

## Optimizing Treatment and Transition from Pediatric to Adult Care

March 4–6  
**2019**  
Cambridge, MA

### Education for:

PHYSICIANS, NPs, and PAs in:

- Pediatrics
- Internal Medicine
- Family Medicine
- Medicine-Pediatrics
- Pediatric Subspecialties
- Medical Specialties and Subspecialties

...and **Psychologists, Social Workers, and Counselors** who support young adults with chronic conditions and their families



Under the direction of  
Niraj Sharma, MD, MPH

- Arthritis
- Autism
- Cancer Survivorship
- Cerebral Palsy
- Congenital Heart Disease

- Cystic Fibrosis
- Diabetes
- Down Syndrome
- Epilepsy
- HIV/AIDS

- Inflammatory Bowel Disease
- Intellectual Disability
- Spina Bifida
- Solid Organ Transplant
- Sickle Cell Disease

Earn up to

25.00 AMA PRA Category 1 Credits™  
24.00 AAFP Prescribed credits

25.00 ABP MOC points  
25.00 ABIM MOC points

**Register at [TCC.HMSCME.com](http://TCC.HMSCME.com)**





# HARVARD MEDICAL SCHOOL

## Reasons to Attend

- New management approaches for chronic conditions in adolescents and young adults
- Tools for assessment of transition readiness and self-management
- Transition timing and timelines, checklists and resources
- Best practices for communication and goal setting with patients and families
- Multidisciplinary care coordination and integration
- Evidence-based quality improvement strategies
- Legal and financial supportive decision-making for patients
- Practice redesign and team-based care
- Updates for sexuality and fertility with chronic disease

## Take-Home Resources

- Transition checklists
- Sample transition curricula
- Readiness assessments
- Transition plans
- Transition policies
- Up-to-date transition coding and reimbursement tip sheet

## Who Attends

PHYSICIANS, NPs, and PAs in:  
Pediatrics  
Internal Medicine  
Family Medicine  
Medicine-Pediatrics  
Pediatric Subspecialties  
Medical Specialties and  
Subspecialties

...and *Psychologists, Social Workers, and Counselors* who support young adults with chronic conditions and their families

## Registration Information

Course #734749-1902	After January 31, 2019	<b>On or before January 31, 2019</b>
<b>Course Tuition</b>	\$945	<b>\$845 (Save \$100)</b>

*Tuition includes all continental breakfasts, and daily morning and afternoon coffee breaks. Complimentary internet access will be provided in the meeting room throughout the course.*

*All attendees of Young Adults with Chronic Conditions: Optimizing Treatment and Transition from Pediatric to Adult Care will receive electronic access to course materials.*

### Registration, Payment, Confirmation and Refund Policy

Registrations for Harvard Medical School CME programs are made via our secure online registration system. To register for this course, please visit the course website at [TCC.HMSCME.com](http://TCC.HMSCME.com).

At the end of the registration process, a \$10 non-refundable processing fee will be added to your registration, and you will have the choice of paying by check, credit card (Visa, MasterCard, or American Express), or wire transfer in USD. If you are paying by check (draft on a United States bank) or by wire transfer, the online registration system will provide you with instructions for remitting your course fees. Postal, telephone, fax, and cash-payment registrations are not accepted. Fees shown in USD.

Upon receipt of your paid registration, an email confirmation will be sent to you. Be sure to include an email address that you check frequently. Your email address is used for critical information, including registration confirmation, evaluation, and certificate. Refunds, less an administrative fee of \$75, will be issued for all cancellations received two weeks prior to the start of the course. Refund requests must be received by email. No refund will be issued should cancellation occur less than two weeks prior. "No shows" are subject to the full course fee and no refunds will be issued once the conference has started.

### Venue



#### Royal Sonesta Boston

40 Edwin H. Land Boulevard  
Cambridge, Massachusetts 02142  
617-806-4200

### Accommodations\*

A limited number of discounted rooms have been reserved at Royal Sonesta Boston until February 8, 2019. You can call the hotel reservation line to make a room reservation: 617-806-4200. Please specify that you are enrolled in this course in order to request the reduced room rate. To make your discounted reservation online by February 8, please visit the course website at [TCC.HMSCME.com](http://TCC.HMSCME.com) and click on the dedicated link on the Venue page.

*\*Please note that the discounted rooms may sell out before the deadline.*

**Please do not make non-refundable travel arrangements until you have received an email from our office confirming your paid registration.**

### Inquiries

By phone: 617-384-8600, Monday-Friday, 9 AM to 5 PM (ET) or by email: [CEPrograms@hms.harvard.edu](mailto:CEPrograms@hms.harvard.edu)

Register at [TCC.HMSCME.com](http://TCC.HMSCME.com)