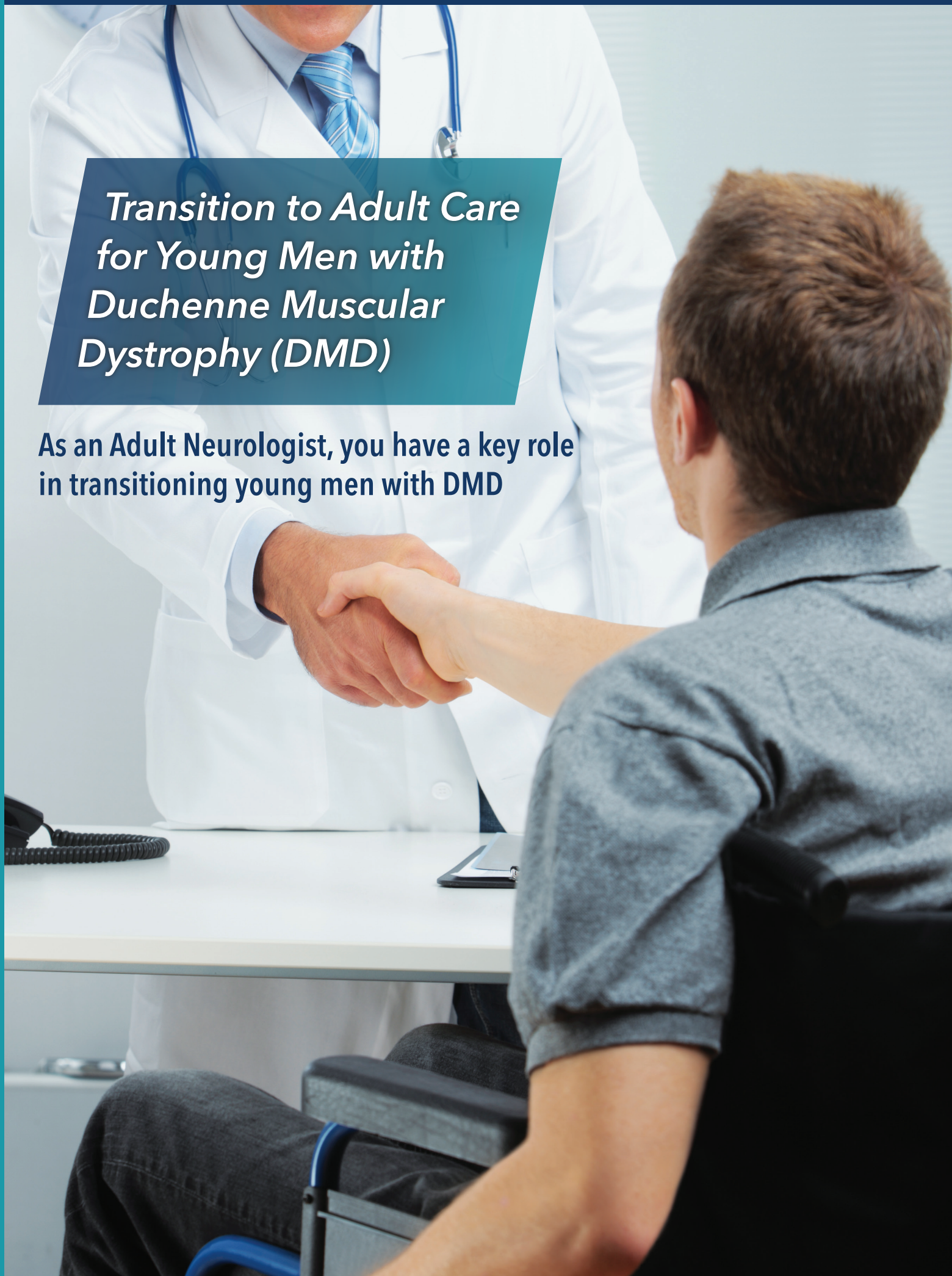
GUIDE FOR ADULT NEUROLOGISTS

Transition to Adult Care for Young Men with Duchenne Muscular Dystrophy (DMD)



As an Adult Neurologist, you have a key role in transitioning young men with DMD

YOU ARE IN A UNIQUE POSITION TO HELP YOUNG MEN WITH DMD TRANSITION FROM PAEDIATRIC TO ADULT CARE

YOUR INVOLVEMENT IS CRITICAL IN THE TRANSITION TO ADULT CARE

DMD, the most common genetic paediatric neuromuscular condition, is characterised by progressive decline in muscle function, leading to loss of ambulation, respiratory and cardiac failure, and subsequent early death.[1-3]

- The transition to adult DMD care is the process of transferring young adults with DMD from paediatric to adult-oriented healthcare[4,5]
- In chronic diseases, transitional planning and intervention are not consistently provided and patients are at higher risk of morbidity and mortality following transition[6]
- During and after the transition period, it's important for the patient to continue with specialist care and stay on treatment[7-9]

YOU CAN HELP PATIENTS WITH DMD AS THEY FACE A NUMBER OF CHALLENGES

Transition to adult care typically occurs at an age when patients desire greater autonomy. At the same time, progression of DMD may occur, resulting in loss of function, greater healthcare needs, and increased reliance on others.[7]

In addition, the patient may:

- lack understanding of the progression of DMD[7,8]
- have insufficient awareness of the need for ongoing treatment and specialist care[6,7,10]
- be overwhelmed by the need to navigate an unfamiliar adult healthcare system[6]
- be unprepared for new adult care responsibilities due to parents' attempts to protect and help their children[10,11]

YOUR ENGAGEMENT AND SUPPORT IS CRUCIAL FOR PATIENTS

Your active support is important for the patient as he assumes greater independence in managing DMD and engages in his care and treatment decisions.[7]

To facilitate the transition to adult care, you should understand:

- the progression of DMD[7]
- the care and treatment of adults with DMD[9]
- how the transition process can affect health outcomes and key aspects of adult life[6,7,10]

AN IDEAL TRANSITION FROM PAEDIATRIC TO ADULT CARE FOR YOUNG MEN WITH DMD

1 REFERRAL/ INTRODUCTION

Paediatric Neurologist introduces the case to Adult Neurologist and educates Adult Neurologist about DMD[12]

2 ADULT NEUROLOGIST/ PATIENT DISCUSSION

Adult Neurologist has introductory meeting with patient months in advance of official transfer of care to establish relationship[6,9]

3 FIRST PATIENT VISIT WITH ADULT NEUROLOGIST

Patient has first visit with Adult Neurologist; transition considered complete[12]

4 SUBSEQUENT PATIENT VISITS WITH ADULT NEUROLOGIST

Patient and Adult Neurologist discuss goals, evaluate needs, and adjust medications if necessary[7,9,10]

TAKE THESE ACTIONS EARLY TO HELP FACILITATE THE TRANSITION TO ADULT CARE

- Learn about DMD and the disease continuum into adulthood[7]
- Review the history of the patient case with the Paediatric Neurologist in advance of the first official visit[12]
- Engage early with the patient in an introductory meeting[6,9]
- Empower the patient to take an active role in his care and medical decisions[6]

ACTIVELY ENGAGE THE PATIENT AS HE TRANSITIONS TO ADULT CARE

CHECKLIST OF ACTION ITEMS FOR ADULT NEUROLOGISTS AT EACH KEY STAGE OF THE TRANSITION PROCESS

1 REFERRAL/INTRODUCTION

Patient is referred; case is introduced by Paediatric Neurologist

- ☐ Schedule/confirm introductory appointment with patient—to be held months in advance of official transfer of care[6,9]
- ☐ Review patient history and DMD educational materials received from the Paediatric Neurologist[12]
- ☐ Meet with the Paediatric Neurologist to discuss DMD, its management, and the patient's history[10,12]

2 ADULT NEUROLOGIST/PATIENT DISCUSSION

Meet with patient months in advance of official transfer of care to establish relationship

- ☐ Assess how anxious the patient is about taking responsibility for his health[6,13,14]
- ☐ Give the patient a choice to attend appointments without parents/caregivers[13,15]
- ☐ Discuss and answer questions about the adult care setting to help the patient more proactively manage his own care[6,10]

3 FIRST PATIENT VISIT WITH ADULT NEUROLOGIST

First official visit with patient conducted; transition considered complete

- ☐ Perform appropriate diagnostic tests as per the standard-of-care guidelines[9]
- ☐ Review history of disease with patient and discuss current treatment plan[6,13,16]
- ☐ Set expectations for the adult-care setting, including patient autonomy and self-management[6,16]

4 SUBSEQUENT PATIENT VISITS WITH ADULT NEUROLOGIST

Continue to discuss goals, evaluate needs, and adjust medications if necessary with patient

- ☐ Involve the patient in decisions regarding his care and any changes to medication[6,7,9,10]
- ☐ Discuss patient goals, needs, and desires (eg, independence, education, relationships)[2,6]

MULTIDISCIPLINARY CARE IS A VITAL PART OF THE ONGOING MANAGEMENT OF ADULTS WITH DMD

- It may be important to connect with adult specialists in the following areas as required to best support the transitioning patient[7,9]:
  - respiratory care
  - cardiology
  - renal care
  - physiotherapy and musculoskeletal medicine
  - nutrition and bowel health
  - bone health
  - psychosocial care
  - endocrinology
  - speech and language therapy
  - occupational therapy
  - clinical psychology
  - social work or care coordination
  - palliative care

As an Adult Neurologist

Your knowledge and support is critical to help young men with DMD transition successfully to adult care

YOUR ACTIVE INVOLVEMENT CAN HELP ENSURE A POSITIVE TRANSITION EXPERIENCE

- Learn about DMD and the complex needs of adults with the disease[6,7,9,10]
- Meet with Paediatric Neurologist early to initiate transfer of care[12]
- Meet with patient months in advance of official transfer of care to establish a relationship[6,9]

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