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The Development of the Medical Transfer Packet for Transition of Care of the Pediatric Headache Patient

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One of the key roles that pediatric providers play in caring for adolescents and young adults (AYA) with chronic diseases is transition to adult care. Although there are no specific guidance documents on how to transition AYA with headache disorders to adult care, there is a consensus statement from the American Academy of Neurology (AAN) on the neurologist's role in supporting transition of AYA with neurological disorders to adult care.¹ In this statement, the authors outlined 8 principles that should guide the transition process; one of these items pertains to the child neurologist's role in identifying an appropriate adult provider and supplying this provider with a transfer packet upon transfer of care. The transfer packet is supposed to comprise a transition plan and a medical summary that includes: diagnosis, current treatments, previous treatments, diagnostic assessments, past procedures and protocols for acute care. The consensus document also recommends that the patient and family routinely be provided with an updated copy of this transfer packet. In addition to these AAN guidelines, transition from pediatric to adult neurological care is also one of the elements included in the AAN's child neurology quality measures set. In this quality measures set, the numerator statement includes a requirement for a medical transition of care plan, which should comprise a medical and surgical history related to the neurological condition, current and past neurological medications and their side effects, as well as details on past and future investigations related to the neurological condition.²

In addition to being recommended by the AAN, transfer packets are one of the most commonly used structured health care transition interventions.³ Structured health care transition interventions, including transfer packets, can promote AYA readiness for transition of care⁴ and can improve transition outcomes.⁵ In addition, when planning transition of care for AYA with primary headache disorders, transfer packets may be particularly valuable due to the complexity of the clinical picture. Patients with primary headache disorders often have a fluctuating clinical course,⁶ with evolving needs over time. In addition, there is a wide and expanding breadth of acute and preventive treatment options for primary headache disorders,^{7,8} and due to a lack of data to guide personalized care, these treatments are currently selected on a "trial and error" basis or based on comorbidity profiles. Given these complexities, it is critical for accepting care providers to understand the evolution of the patient's disease over time and what treatments have been tried in the past, as this guides decision-making about future treatment choices. Thus, not only is there data to support the

use of transfer packets in transition of care, but there is also impetus to implement them for AYA with primary headache disorders given the potential complexity of disease courses and the potential variety and volume of past treatment trials.

The objective of this project was to develop a medical transfer packet for AYA with headache disorders based on expert consensus and feedback. The purpose of this transfer packet is to set standards for written communication from referring to accepting providers during transition of care, and to ensure that all critical elements of the medical summary are included in these standards, as outlined in the AAN consensus statement¹ and quality measures set.² It is important to note that this transition tool was designed for AYA with headache disorders who are being cared for by a pediatric neurologist or a headache specialist, and who require ongoing neurological care for their headache disorder. Although we propose that this transfer packet be used to guide written communication from referring to accepting providers, we acknowledge that the packet provided may not be the best means of written transfer communication in some practice settings. For example, electronic medical records (EMR) may be used to create a similar transfer packet template and may be preferable in that they may facilitate auto-population of data elements into an EMR-based electronic transfer packet based on prior data points.

In order to develop a transfer packet for AYA with headache disorders, a draft transfer packet was created by a pediatric headache specialist (SLO) and sent electronically to 21 other pediatric headache specialists throughout North America for the purposes of soliciting feedback. Fourteen of the pediatric headache specialists provided feedback on the draft packet (all co-authors listed), and this feedback was used to create a second draft of the transfer packet. This second draft of the transfer packet was then sent to 10 adult headache specialists who are on the board of the Canadian Headache Society (CHS). Following review and comments by the CHS board, a third draft of the transfer packet was created and circulated amongst all of the co-authors of this manuscript. Further changes were then made that aimed to incorporate all stakeholder feedback and to optimize the transfer packet both from a content perspective and with regards to feasibility of implementation. All co-authors reviewed and approved of the final version of the transfer packet.

In summary, AYA with headache disorders who are expected to have ongoing neurological care needs into adulthood often require transition to adult neurology care and structured health care transition interventions can be used to optimize this process. As recommended by the AAN, transferring pediatric providers should endeavor to standardize and facilitate the transition process through the use of medical transfer packets and other transition strategies.^{1,2} To meet this need, we have created a medical transfer packet that aims to facilitate communication of the medical summary from the referring pediatric headache provider to the accepting adult provider. It is our hope that this transfer packet will improve communication between providers and facilitate medical information sharing in the transition of care process, given that similar interventions in other patient populations have been shown to improve transition outcomes.⁵

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Abbreviations:

AAN	American Academy of Neurology
AYA	adolescents and young adults
CHS	Canadian Headache Society
EMR	electronic medical records

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