

Developing a patient accessible version of the 2016 National Clinical Guideline for Stroke for stroke survivors and their carers

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Background

The 5th edition of the Royal College of Physicians'(RCP) National Clinical Guideline for Stroke (NCGS) was published in October 2016 by the Intercollegiate Stroke Working Party (ICSWP). It provides evidence-based recommendations along the entire stroke care pathway for stroke clinicians. A lay version for each NCGS edition has been produced as an informational booklet. After low dissemination rates of previous editions, the need to produce an updated version that could reach a larger audience of stroke survivors and carers was identified.

Methods

The multidisciplinary implementation group, responsible for all guideline content, included three stroke survivors. Patient groups, including people with aphasia, were regularly consulted about content and formats for the patients' version. Members of the ICSWP and the national stroke charity provided feedback and revisions.

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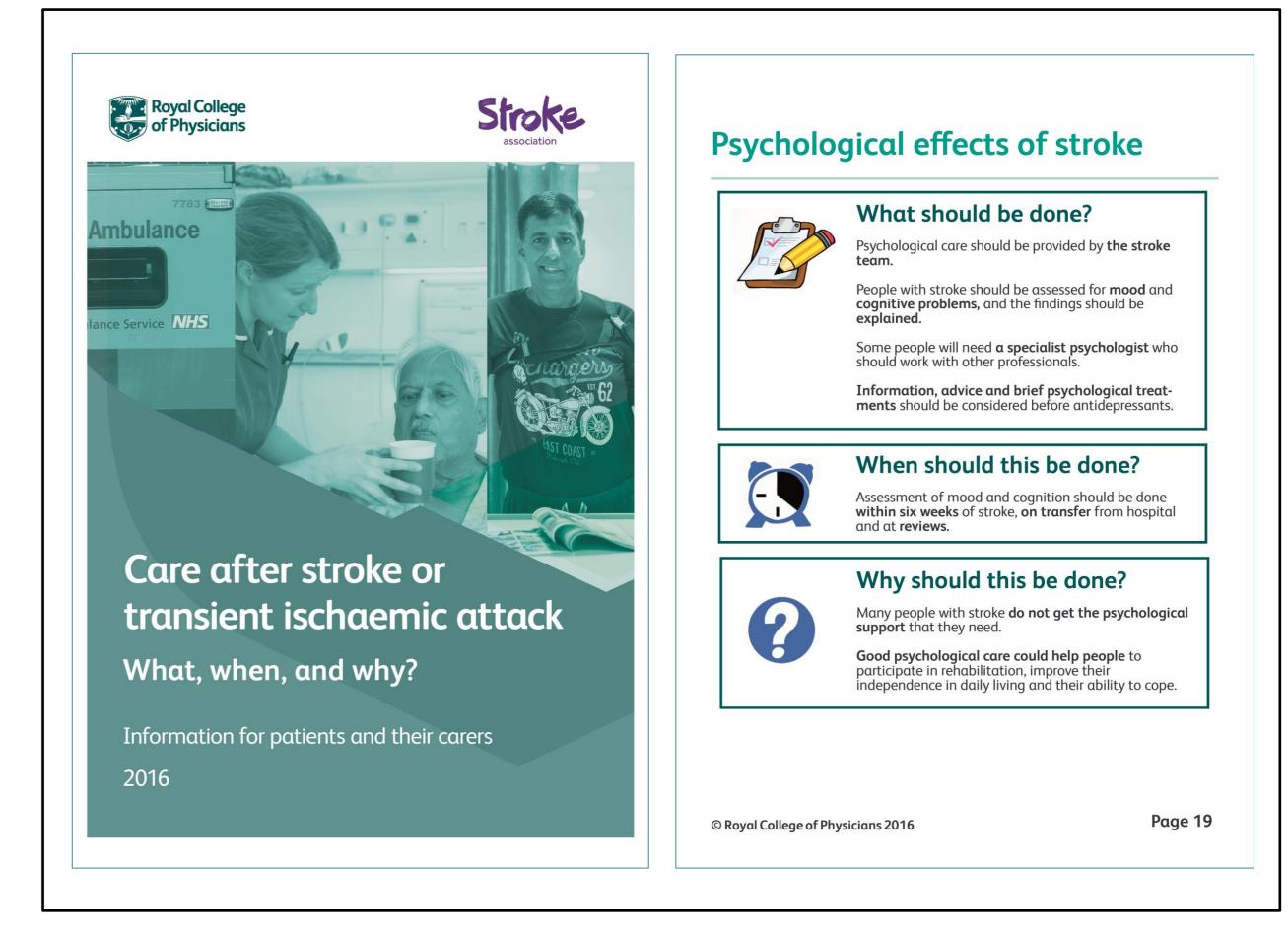
Figure 1: Web based and downloadable electronic versions of patient accessible stroke guideline

Results

An "easy-read" guideline was produced in print (booklet). Electronic (downloadable PDF, online eBook and ePub/kindle) and audiobook (mp3) formats were also made available.

This patient accessible stroke guideline, written by stroke survivors, for patients and carers, presents key standards in stroke care using pictures, symbols and readable text for people with communication and cognitive impairments. Within a six-month period, over 3,600 printed copies of the booklet were disseminated at national stroke conferences, in hospitals, and through patient groups. Furthermore, the electronic and audio versions were downloaded and accessed over 2,300 times. Feedback from patients and clinicians indicate the accessibility and usefulness of this as an educational resource.

Figure 2: Sample pages from "easy-read" booklet



Conclusion

Knowledge of current stroke care standards can be used as a tool for patients and carers to support discussions about treatment and advocate for care after being in hospital. Wider audiences can be reached when presenting this information in accessible language, clear layouts, and in multimedia formats.