Supplementary Material:

Table 1

 Experienced of a bereaved carer

Experience of a lady whose father had a stroke in the UK-and a summary of the key learning points

“A severe stroke on a loved one has a profound impact on the family. My father, an active, independent man, became severely disabled, requiring 24-hour care. Life was never to be the same again.

Our journey involved a turbulence of emotions as we helplessly watched events unfolding, wishful of an improvement that would never come.

My father’s care saw him hospitalised for 5 months, dying two months later in a care home following a further stroke. The emphasis was continually on rehabilitation, which we encouraged. Unbeknown to us this was a physical impossibility. As time passed, dad became emotionless, discouraged and would stare with great sadness – almost saying, “Is this what life has become?” Our expectation of a recovery was fading fast.

Families hope for the best but need to be prepared for the worst. In order to avoid family disagreement on the course treatment, open and honest conversations regarding the extent of any recovery or life expectancy are essential. Being shown the brain scan helped us to accept the severity of the stroke.

Simple acts of kindness and compassion mean a lot. In his final weeks, the personal care provided by staff was very comforting.”

Key learning

- Stroke has a profound psychological effect on family as well as patient
- Open and honest discussions about stroke severity and likely outcome are essential to avoid false hope and treatments that have no realistic chance of making a difference

The power of kind and compassionate care should not be underestimated
Search strategy and results

MEDLINE Ovid Search strategy*: Palliative Care in Stroke 2020:

1. palliative medicine/
2. palliative care/ or terminal care/ or hospice care/ or hospices/
3. "hospice and palliative care nursing"/
4. advance care planning/ or advance directives/
5. attitude to death/
6. (((palliative or terminal) adj3 (unit$ or care$ or consultation or medicine or treatment$ or hospital$ or nurs$ or team$ or specialist$ or service$ or program$ or pathway)) or hospice$).tw.
7. ((dying or bereavment or grief or griev$ or death$ or "loss of independence") adj3 (process or care or comfort or relief or strateg$ or plan$ or model$ or intervention$ or pain$)).tw.
8. (end of life or end-of-life).tw.
9. or/1-8
10. cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp cerebral small vessel diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vasospasm, intracranial/ or vertebral artery dissection/ or carotid stenosis/ or exp carotid artery injuries/ or intracranial arterial diseases/ or cerebral arterial diseases/ or infarction, anterior cerebral artery/ or infarction, middle cerebral artery/ or infarction, posterior cerebral artery/ or exp carotid arteries/ or endarterectomy, carotid/ 
11. (stroke or poststroke or post-stroke or cerebrovasc$ or (cerebr$ adj3 vasc$) or CVA$ or apoplectic or apoplex$ or (transient adj3 isch?emic adj3 attack) or tia$ or SAH or AVM or (cerebral small vessel adj3 disease)).tw.
12. ((cerebr$ or cerebell$ or arteriovenous or vertebrobasil$ or interhemispheric or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or MCAS or ((anterior or posterior) adj3 circulat$) or lenticulostrate or (basilar or brachial or vertebr$) adj3 arter$)) adj3 (disease or damage$ or disorder$ or disturbance or dissection or syndrome or arrest or accident or lesion or vasculopathy or insult or attack or injury or insufficiency or malformation or obstruct$ or anomal$)).tw.
13. (((cerebr$ or cerebell$ or vertebrobasil$ or interhemispheric or hemispher$ or intracran$ or corpus callosum or intracerebral or intracortical or intraventricular or periventricular or posterior fossa or infratentorial or supratentorial or MCAS or ((anterior or posterior) adj3 circulation) or basal ganglia or (basilar or brachial or vertebr$) adj3 arter$) or space-occupying or brain ventricle$ or subarachnoid$ or arachnoid$) adj3 (h?emorrhage or h?ematoma or bleed$ or microh?emorrhage or microbleed)) or encephalorrhagia or hematencephal$).tw.
14. (((cerebr$ or cerebell$ or arteriovenous or vertebrobasil$ or interhemispheric or hemispher$ or intracran$ or corpus callosum or intracerebral or intracortical or intraventricular or periventricular or posterior fossa or infratentorial or supratentorial or MCAS or ((anterior or posterior) adj3 circulation) or basal ganglia or (basilar or brachial or vertebr$) adj3 arter$) or space-occupying or brain ventricle$ or lacunar or cortical or ocular) adj3 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$ or vasospasm or obstruct$ or vasoconstrict$)).tw.
15. or/10-14
16. (2015$ or 2016$ or 2017$ or 2018$ or 2019$ or 202$).dp. or 20140101:20301231.(ep).
17. 9 and 15
Due to the ongoing COVID-19 crisis the WHO International Clinical Trials Registry Platform had limited accessibility because of increased traffic. Therefore, we used their basic function to search “stroke AND palliative” and “end-of-life AND stroke”.

**Selection criteria**

No language restrictions were applied.

Inclusion criteria: primary research studies of any design, systematic reviews, clinical guidelines, policy statements

Exclusion criteria: conference abstracts; case reports; subarachnoid haemorrhage; paediatrics; papers on stroke and organ donation/brain death, prognostication, or generic carer support post-stroke.

We also searched reference lists of relevant papers.

**Results of the searches**

*Palliative Care in Stroke, 2020*

This search identified 4508 citations. After removal of 1237 duplicates, the remaining titles and abstracts were screened by one of two reviewers (EC, GM) and 3029 irrelevant articles were excluded. Full texts were viewed by either GM or EC, 164 excluded, leaving 73 articles that addressed our broad aims.

These articles were tagged by EC into four areas: scale of the palliative care problem, management approaches, service provision, shared decision making. Information was extracted on ‘the scale’ of the problem by EC, GM extracted information on management approaches and service provision, and MS and RL extracted information on shared decision making.

The articles from low or middle income countries were reviewed by RM.
Table 2 A summary of the evidence for the management of each of the palliative care problems identified in the initial searches and in the WHO definition of palliative care. This evidence was obtained by searching the Cochrane library for reviews in stroke published from 2015 onwards, and if we found no reviews in stroke, we searched the rest of the Cochrane Library and the Database of Research in Stroke (DORIS).

| Source of evidence | Summary of evidence |
|--------------------|---------------------|
| **Pain**           | Non Cochrane review of shoulder pain\(^67\). Cochrane reviews of neuropathic pain (but not specifically in stroke) \(^68,69\) | Low quality evidence for acupuncture for shoulder pain\(^67\). Neuropathic pain: limited evidence for pregabaline\(^69\) insufficient evidence about cannabinoids\(^68\) |
| **Dysarthria**     | Cochrane review of dysarthria in stroke (2017)\(^70\) | Insufficient evidence to guide management |
| **Dry mouth**      | Cochrane review of parenteral fluids in stroke \(^36\) | Insufficient evidence because the included trials did not report dry mouth as an outcome |
| **Dyspnoea**       | No Cochrane review specifically in stroke. Cochrane review of opioids for breathlessness at the end of life.\(^71\) | Limited evidence for opioids; the trials included people with cancer, heart failure and lung disease but not stroke |
| **Constipation**   | No Cochrane review specifically in stroke; non-stroke Cochrane reviews published before 2015 | Limited evidence about best approach |
| **Aphasia**        | Cochrane stroke review (2016)\(^72\) | Speech and language therapy improve communication but trials were restricted only to those who were medically stable |
| **Anxiety**        | Cochrane Stroke review 2017\(^73\) | Insufficient evidence to make recommendations about management of anxiety after stroke. No trials considered existential distress |
| **Depression**     | Cochrane Stroke review 2020\(^35\) | Insufficient evidence for people with severe stroke |
| **Urinary incontinence** | Cochrane Stroke review 2019\(^74\) | Insufficient evidence |
| **Faecal incontinence** | No systematic reviews of interventions in stroke | Insufficient evidence |
| **Nausea and vomiting** | No Cochrane review in stroke | Insufficient evidence |
| **Spiritual needs** | No systematic reviews of interventions in stroke | Insufficient evidence |
| **Delirium**       | One review\(^75\) in terminally ill (not stroke) from Cochrane Palliative Care Group; and several from Cochrane Dementia and Cognitive Improvement Group. | Insufficient evidence |
systematic reviews of interventions specifically in stroke

| Condition | Reviews | Evidence |
|-----------|---------|----------|
| Seizures  | No      | Insufficient evidence |
| Pressure ulcers | Several reviews from Cochrane wound group on prevention and treatment using a range of different approaches, but no reviews specifically in stroke | Insufficient evidence |
| Death rattles | No | Insufficient evidence |

35 Allida S, Cox KL, Hsieh CF, House A, Hackett ML. Pharmacological, psychological and non-invasive brain stimulation interventions for preventing depression after stroke. Cochrane Database Syst. Rev. 2020; 5: Art. No. CD003689.

36 Visvanathan A, Dennis M, Whiteley W. Parenteral fluid regimens for improving functional outcome in people with acute stroke. Cochrane Database Syst Rev 2015; 9: Art No.CD011138.

67 Liu S, Zhang CS, Cai Y, et al. Acupuncture for Post-stroke Shoulder-Hand Syndrome: A Systematic Review and Meta-Analysis. Front Neurol 2019; 10: 433.

68 Mücke M, Phillips T, Radbruch L, Petzke F, Häuser W. Cannabis-based medicines for chronic neuropathic pain in adults. Cochrane Database Syst Rev 2018; 3: Art. No. CD012182.

69 Derry S, Bell RF, Straube S, Wiffen PJ, Aldington D, Moore RA. Pregabalin for neuropathic pain in adults. Cochrane Database Syst Rev 2019; 1: Art. No. CD007076.

70 Mitchell C, Bowen A, Tyson S, Butterfint Z, Conroy P. Interventions for dysarthria due to stroke and other adult-acquired, non-progressive brain injury. Cochrane Database Syst Rev 2017; 1: Art. No. CD002088.

71 Barnes H, Mcdonald J, Smallwood N, Manser R. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane Database Syst Rev 2016; 3: Art. No. CD011008.

72 Brady MC, Kelly H, Godwin J, Enderby P, Campbell P. Speech and language therapy for aphasia following stroke. Cochrane Database Syst Rev 2016; 6: Art. No. CD000425.

73 Knapp P, Campbell Burton CA, Holmes J, et al. Interventions for treating anxiety after stroke. Cochrane Database Syst Rev 2017; 5: Art. No. CD008860.

74 Thomas LH, Coupe J, Cross LD, Tan AL, Watkins CL. Interventions for treating urinary incontinence after stroke in adults. Cochrane Database Syst Rev 2019; 2: Art. No. CD004462.

75 Finucane AM, Jones L, Leurent B, et al. Drug therapy for delirium in terminally ill adults. Cochrane Database Syst Rev 2020; 1: Art. No.CD004770.

76 Porter-Armstrong AP, Moore ZEH, Bradbury I, Mcdonough S. Education of healthcare professionals for preventing pressure ulcers. Cochrane Database Syst Rev 2018; 5: Art. No. CD011620.

77 Joyce P, Moore ZE, Christie J. Organisation of health services for preventing and treating pressure ulcers. Cochrane Database Syst Rev 2018; 12: Art. No. CD012132.