

DRAFT GUIDELINES FOR PUBLIC COMMENT 21ST OCTOBER 2020 **OPEN FOR COMMENT** UNTIL 5TH NOVEMBER 2020

HIBI – Hypoxic Ischemic Brain Injury
OHCA – Out of Hospital Cardiac Arrest
RCT – Randomised Controlled Trial
ROSC – Return of Spontaneous Circulation
WLST – Withdrawal of Life Sustaining Therapies

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1888 1889 [h2]Long-term outcome after cardiac arrest 1890 [h3] Long-term outcome In countries where WLST is uncommon, poor outcome because of HIBI is common. ^{376,416} The 1891 prognosis of patients who are still comatose or in an unresponsive wakefulness state one month after 1892 the cardiac arrest is poor and they rarely recover. 416,417 In contrast, in countries practising WLST, the 1893 majority of survivors are defined as having a 'good' neurological outcome based on global outcome 1894 1895 measures such as Cerebral Performance Categories (CPC), modified Rankin Scale (mRS) or the Glasgow Outcome Scale/Extended (GOS/E). ^{279,398,418-420} However, these measures are not sufficiently 1896 1897 sensitive to capture the problems that many of the survivors experience, including cognitive, emotional and physical problems and fatigue. 421-423 In fact, approximately 40-50% of the survivors 1898 have long-term cognitive impairments. ^{219,424,425} Impairments are mostly mild to moderate and. 1899 1900 although all cognitive domains can be affected, most problems are seen in memory, attention, processing speed and executive functioning (e.g. planning, organisation, initiation, flexibility). ^{219,421,424}-1901 ⁴²⁶ In general, most cognitive recovery occurs during the first three months after the cardiac arrest. ⁴²⁷ 1902 1903 1904

1905	Emotional problems are also common. Three to six months after the cardiac arrest anxiety is present
1906	in 15-30% of the survivors and remains in 15-23% at 12 months. ⁴³⁰⁻⁴³² Depressive symptoms range
1907	from 13-32% at 3-6 months and decrease to 5-15% at 12 months. 430-433 Symptoms of post-traumatic
1908	stress remain in about a quarter of the survivors. 422,430,433,434 Furthermore, some survivors show
1909	behavioural problems, such as aggressive/uninhibited behaviour or emotional lability. 425
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1911	Fatigue is also frequently reported and is present in approximately 70% of the survivors at six months
1912	and remains in half of the survivors one year after the event. 430,435,436 Physical problems, including rib
1913 1914	fractures, muscle weakness and ambulation difficulties, have also been reported. 423,430,437,438 However, the impact of survival on physical function has received little attention; when compared
1915	with age and gender-matched populations, reduced physical functioning has been reported in
1916	survivors at 3-months, ⁴³⁹ 6-months, ⁴³⁸ 12-months ⁴²⁰ and three years. ⁴³⁷ Almost half of survivors report
1917	limitations because of physical difficulties at 6-months, 438 with up to 40% describing mobility
1918	problems ^{420,425,430,440} and limitations in usual activities at 12-months. ^{420,430,440}
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1920	After discharge, most survivors are able to return home and only a small percentage (1–10%) need to
1921	be admitted to a long-term care facility. 430,440,441 The large majority (82–91%) are independent in their
1922	basic activities of daily living (ADL). 218,424,437,440 Although most survivors are able to resume their pre-
1923	arrest activities, they experience more restrictions in societal participation compared with myocardial
1924	infarction patients. 430,436 Cognitive impairments, depression, fatigue and restricted mobility are
1925 1926	negative predictors for future participation. 436
1927	Of those who were previously working, 63-85% are able to return to work, although some need to
1928	420,430,436,437,440,442-444 adapt their working hours or activities. 420,430,436,437,440,442-444 Decreased likelihood of return to work is
1929	associated with cognitive problems and fatigue, unwitnessed OHCA, absence of bystander CPR,
1930	female gender, higher age and lower socio-economic status. 436,439,442-444
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1932	General health-related quality of life is, on average, good and overall scores approach normal
1933	population values, as was shown in two systematic reviews and confirmed in several more recent
1934	studies. 218,420,440,445,446 Cognitive impairments, emotional problems and female gender are associated
1935	with a lower quality of life. 420,428,438,439,447-452 However, general health related quality of life is, on
1936	average, reported as good with overall scores approaching normal population values, as was shown in
1937	two systematic reviews and confirmed in several more recent studies. 218,420,440,445,446 However, such
1938	generic assessments lack sufficient granularity to comprehensively capture the breadth of problems

1939	experienced by survivors, with the result that the impact of cardiac arrest survival may be
1940	incompletely captured. 279 Supplementing such generic assessment with condition or problem-specific
1941	assessment is recommended. 279
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1943	More detailed information on recovery and long-term outcome after cardiac arrest, as well as a
1944	description of the current rehabilitation practices in Europe can be found in the epidemiology section
1945	of the European Resuscitation Council Guidelines. 453
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1948	[h3] In-hospital assessment and follow-up after hospital discharge
1949	[h4] Early rehabilitation and assessment during hospital phase
1950	There are no studies of early rehabilitation interventions for cardiac arrest survivors specifically but
1951	there is substantial overlap with the post-intensive care syndrome (PICS). For other ICU patients,
1952	interventions of early mobilisation and prevention of delirium are described, and similar interventions
1953	are thought to be useful for cardiac arrest patients as well. 423,454-456 Recommendations in the UK
1954	National Institute for Health and Care Excellence (NICE) guidelines for rehabilitation after critical
1955	illness suggest that individualised rehabilitation plans and information should be provided before
1956	discharge from the ICU and the hospital, based on functional assessments of physical and non-
1957	physical (e.g. cognitive and emotional) impairments. 457 However, a recent AHA Scientific Statement
1958	focusing on survivorship highlights that discharge planning and organisation of further rehabilitation
1959	needs after cardiac arrest is often lacking. 423
1960	We therefore recommend providing information and performing functional assessments of physical
1961	and non-physical impairments before discharge from the hospital to identify potential rehabilitation
1962	needs and arrange referral for rehabilitation if indicated (Figure X.5).
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1964	[h4] Follow-up and screening after hospital discharge
1965	Although cognitive impairments, emotional problems and fatigue are common after cardiac arrest,
1966	these 'invisible problems' are not always recognised by healthcare professionals. 428,436,439,443,452 Since
1967	these problems have a significant impact on long-term outcome and quality of life, follow-up should
1968	be organised in such a way that these problems are detected early enabling appropriate care or
1969	rehabilitation to be arranged. 458-460
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1971	Evidence on this subject is scarce but results from one RCT showed that an early intervention service
1972	for cardiac arrest survivors and their caregivers improved emotional well-being and quality of life,

resulted in a faster return to work and was cost-effective. ^{461,462} This individualised programme is provided by a specialised nurse, starts soon after discharge from the hospital and comprises one to six consultations during the first three months. The intervention consists of screening for cognitive and emotional problems, provision of information and support, and referral to further specialised care if indicated. ^{463,464} There are several other examples of how follow-up after cardiac arrest can be organised. ^{460,465,466} UK NICE guidelines for rehabilitation after critical illness likewise recommend a follow-up and reassessment for physical and non-physical problems 2-3 months after discharge to enable identification of remaining problems and to provide further support as needed. ⁴⁵⁷ For cardiac arrest survivors, reassessments have also been suggested at 3, 6 and 12 months. ⁴²³

We therefore suggest the systematic follow-up of all cardiac arrest survivors within three months following hospital discharge which should, at least, include cognitive screening, screening for emotional problems and fatigue, and the provision of information and support for patients and their

1986 family (Figure X.5).

[h4] Screening for cognitive problems

To screen for cognition, the patient can be asked about common cognitive complaints, such as memory problems, attention difficulties, distractibility, slowness in thinking, irritability and problems in initiation, planning, multi-tasking or flexibility. Family members can also provide useful insight into changes in cognition and behaviour. A structured questionnaire, such as the Informant Questionnaire of Cognitive decline in the Elderly - Cardiac Arrest version (IQCODE-CA) or the Checklist Cognition and Emotion (CLCE-24), may be used. 467,468 Formal cognitive screening is recommended because patients are not always aware of their cognitive impairments. 429,458,469 We suggest use of the Montreal Cognitive Assessment (MoCA), which takes approximately 10 minutes to administer, is easy to use and freely available in many languages (see www.mocatest.org). 466,469-471 If there are signs of cognitive impairment, consider referral to a neuropsychologist for more extensive neuropsychological assessment or another specialist in cognitive rehabilitation, such as an occupational therapist, should be considered. 472

[h4] Screening for emotional problems and fatigue

To screen for emotional problems, the presence of emotional symptoms, including symptoms of anxiety, depression and posttraumatic stress, can be explored. Questionnaires, such as the Hospital Anxiety and Depression Scale (HADS), may be useful. 423,459,466,473 If severe emotional problems are detected we suggest referral to a psychologist or psychiatrist for further evaluation and treatment.

2007	We also suggest assessing the presence of fatigue; however, assessment guidance in this population
2008	is currently lacking. In case of severe fatigue consider referral to a specialist in rehabilitation medicine
2009	for advice on appropriate care.
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2011	[h4] Provision of information and support for survivor and family members
2012	Exploring the need for and subsequent provision of appropriate information to patients and their
2013 2014	family, preferably both in oral and written form, is recommended. ⁴⁷⁴ The active engagement of survivors and their family members to better understand their needs and how they would like to
2015 2016	receive such information, is recommended as part of this process. 423 Information should cover not only medical subjects such as cardiac disease, risk factors, medication and ICD, but can also address
2017	other topics such as potential physical, cognitive and emotional changes and fatigue, resuming daily
2018	activities, driving and work, relationship and sexuality. 463,474-477
2019	It is also important to monitor the well-being of family members because the impact and burden can
2020	be substantial. 476,478 Partners often have emotional problems, including symptoms of anxiety and
2021	posttraumatic stress, especially in women and those who witnessed the resuscitation. 479,480 Consider
2022	referral to a social worker, psychologist or psychiatrist when indicated.
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2025	[h2] Rehabilitation after cardiac arrest
2026	[h3] Neurological rehabilitation
2027	In the presence of severe HIBI, patients may require inpatient neurological rehabilitation and,
2028	although the evidence is limited, several small retrospective studies have shown that functional
2029 2030	improvements can be achieved, reducing the burden of care on the family and society. 481-483
2031	Although specific guidelines and evidence for neurological rehabilitation after cardiac arrest is lacking,
2032	there is more evidence and multiple clinical practice guidelines for other types of acquired brain
2033	injury such as traumatic brain injury and stroke which can guide the treatment of patients with HIBI
2034 2035	due to cardiac arrest. 484-486 These guidelines provide practical recommendations on topics such as motor function, physical rehabilitation, cognition, communication, activities of daily living and
2036	psychosocial issues. Guidelines on rehabilitation after critical illness/ post-intensive care syndrome
2037 2038	(PICS) can also be useful. 457,487-489
2039	[h3] Cardiac rehabilitation

2040	Many cardiac arrest survivors are eligible to enrol in a cardiac rehabilitation programme. ⁴⁹⁰ There is
2041	evidence that cardiac rehabilitation reduces cardiovascular mortality and hospital admissions,
2042	improves quality of life, and is cost-effective. 490-493 Cardiac rehabilitation programmes are mostly
2043	generic programmes, in which patients with different cardiac diseases, e.g. post-acute coronary
2044	syndrome, heart failure or post cardiac surgery, can participate. It involves exercise training, risk
2045	factor management, lifestyle advice, education and psychological support. 491 Cardiac rehabilitation is
2046	frequently offered as a centre-based out-patient service, but can also be organised in a home-based
2047	setting in combination with telemonitoring. 494 In specific cases it can be provided as an inpatient
2048	programme. 491 Not all cardiac arrest survivors are eligible for or have access to cardiac rehabilitation,
2049	either because of the cause of the cardiac arrest or because of variation in national or insurance
20502051	policies. ⁴⁹⁵
2052	Within cardiac rehabilitation programmes little attention is paid to potential cognitive problems.
2053	Among cardiac patients in general, cognitive and emotional problems have not been addressed well
2054	in cardiac rehabilitation programmes. 496-498 For cardiac arrest survivors, there are some examples in
2055	which cardiac and cognitive rehabilitation have been integrated, although evidence of effects is still
2056	lacking. 460,466
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2058	[h3] Cognitive rehabilitation, fatigue management and psychosocial interventions
2059	The goal of cognitive rehabilitation is to reduce the impact of cognitive impairments and to improve
2060	overall well-being and daily functioning. 499 It can include additional neuropsychological assessment to
2061	get more insight into the nature and severity of the cognitive impairments and other influencing
2062	factors. Extensive patient education is essential to give the patient and their family more insight into
2063	what has changed in their cognition and behaviour. Compensation strategies, such as memory
2064	strategy training and metacognitive strategy training (e.g. self-monitoring, self-regulation and
2065 2066	planning ahead) and the use of external (memory) aids may be helpful. ⁴⁷² Although there are no specific studies on the effects of cognitive rehabilitation in patients with brain injury caused by cardiac
2067	arrest, a recent evidence-based review on cognitive rehabilitation after stroke and traumatic brain
2068	injury, can serve as a guideline. 472
2069	mgary, can serve as a gardenne.
2070	Fatigue management can be included in cognitive rehabilitation or provided alone. ⁵⁰⁰ [Wylie <mark>2018</mark>
2071	CNC50] There is weak evidence that a 4-week telephone intervention, based on energy conservation
2072	and problem-solving therapy, can be of benefit for cardiac arrest survivors with moderate to severe

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2075	There is also evidence that psychosocial interventions specifically designed for cardiac arrest survivors
2076	can be valuable. Two RCTs showed benefit from nurse-led psychosocial interventions, either by
2077	telephone or face-to-face. 503,504 These interventions addressed self-management, coping strategies,
2078	relaxation, information and health education. 504,505
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2080	There are currently no studies on the effectiveness of social support networks or virtual/online
2081	forums, but these may have additional value as a new and easily accessible form of psychosocial
2082	support and information after cardiac arrest. 423
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