



**PEJABAT KETUA PENGARAH KESIHATAN
KEMENTERIAN KESIHATAN MALAYSIA**

Office of Director General of Health Malaysia, Ministry Of Health Malaysia

ARAS 12, BLOK E 7, PARCEL E
KOMPLEKS KERAJAAN PERSEKUTUAN
62590 PUTRAJAYA

Telefon : 03-88833888

Fax : 03-88831155

RUJ. TUAN :
RUJ. KAMI : KKM87/P1/1/1/3(22)
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Pengarah Kesihatan Negeri,
Pengarah Kesihatan Wilayah Persekutuan Kuala Lumpur,
Pengarah Hospital Kuala Lumpur,

Y Bhg Dato'/ Datin/ Tuan/ Puan,

SURAT PEKELILING KETUA PENGARAH KESIHATAN MALAYSIA BIL 6 / 2008

**GARISPANDUAN PENGURUSAN PESAKIT KANAK-KANAK YANG MENDERITA PENYAKIT
JANTUNG KONGENITAL UNTUK MENJALANI RAWATAN PEMBEDAHAN DI HOSPITAL
NARAYANA HRUDAYALAYA (NH), BANGALORE, INDIA.**

1. TUJUAN

Kertas ini bertujuan untuk memaklumkan kaedah pelaksanaan pengurusan pesakit kanak-kanak yang menderita penyakit jantung kongenital untuk menjalani rawatan pembedahan di Hospital Narayana Hrudayalaya, Bangalore, India.

2. LATAR BELAKANG

Penyakit Jantung Kongenital di kalangan kanak-kanak di Malaysia menurut statistik adalah antara 8 hingga 10 daripada setiap 1,000 kelahiran hidup. Dengan kadar kelahiran semasa ini iaitu 500,000 setahun, bilangan kanak-kanak dengan masalah ini adalah lebih kurang 5,000 orang setahun di mana dua pertiga darinya akan memerlukan rawatan pembedahan.

Di Malaysia, kes-kes pembedahan jantung pediatrik yang kompleks hanya dapat dijalankan di Institut Jantung Negara (IJN) dan di beberapa buah hospital swasta yang lain. Ini menyebabkan masa menunggu yang lama bagi para pesakit untuk dapat menjalani rawatan pembedahan berkenaan.

Sehubungan dengan itu, Jemaah Menteri telah bersetuju supaya kerajaan membiayai kos rawatan pembedahan jantung di Hospital Narayana Hrudayalaya, Bangalore, India bagi pesakit jantung kongenital kanak-kanak yang tidak berkemampuan. Untuk tujuan ini sejumlah RM 2 juta di peruntukkan dari Tabung Bantuan Perubatan.

3. KAEDAH PERLAKSANAAN

3.1 KRITERIA PEMILIHAN PESAKIT UNTUK PEMBEDAHAN

Penentuan dan pemilihan pesakit adalah bergantung kepada keputusan dan cadangan yang dikemukakan oleh Pakar Jantung Pediatrik KKM.

3.1.1 Semua pesakit-pesakit jantung kongenital kanak-kanak yang memerlukan rawatan pembedahan perlulah dirujuk kepada pakar pediatrik kardiologi Kementerian Kesihatan Malaysia untuk penilaian dan pemeriksaan lanjut. Bagi kes-kes yang memenuhi kriteria pembedahan jantung, perlulah dirujuk kepada pegawai kerja sosial perubatan untuk penilaian taraf sosio ekonomi mereka.

3.1.2 Contoh-contoh kes yang tergolong dalam kategori kronik dan stabil adalah di Lampiran 1 dalam Garispanduan.

3.2 KRITERIA PEMILIHAN PESAKIT UNTUK PEMBIAYAAN DANA TABUNG BANTUAN PERUBATAN

Bagi kes-kes yang memenuhi kriteria penilaian pesakit dan layak dari segi taraf sosio ekonomi, perlu dirujuk kepada Sekretariat Tabung Bantuan Perubatan. Bagi pesakit yang memerlukan rawatan pembedahan, penilaian taraf sosio ekonomi perlu dilakukan oleh pegawai kerja sosial perubatan hospital masing-masing. Dan bagi permohonan yang memenuhi kriteria bantuan Tabung Bantuan Perubatan, mereka perlu dirujuk ke sekretariat Tabung Bantuan Perubatan di Bahagian Kewangan. Prosedur oleh Tabung Bantuan Perubatan adalah sebagaimana untuk mana-mana kes lain yang perlukan bantuan dana Tabung Bantuan Perubatan.

4. PELAKSANAAN

Pesakit pediatrik dengan masalah jantung kongenital yang telah memenuhi kriteria pemilihan oleh pakar pediatrik kardiologi dan telah diluluskan untuk pembiayaan dana Tabung Bantuan Perubatan akan dirujuk ke Klinik Medi Assist4U bagi tujuan penyelarasan dengan Hospital Narayana Hrudayalaya dan jika didapati sesuai untuk dibedah di Hospital Narayana Hrudayalaya barulah akan dikendalikan urusan penghantaran pesakit oleh Klinik Medi Assist4U. Perincian pelaksanaan terdapat dalam garis panduan.

Perjanjian berkenaan penghantaran pesakit ke Hospital Narayana Hrudayalaya telah diadakan antara Kementerian Kesihatan Malaysia, Klinik Medi Assist4U dan Hospital Narayana Hrudayalaya bagi membolehkan urusan penghantaran pesakit dan perawatan pesakit dapat berjalan lancar dan kebajikan pesakit terjamin.

5. TINDAKAN DAN TANGGUNGJAWAB

Pengarah Kesihatan Negeri dipertanggungjawabkan memantau pelaksanaan garis panduan ini.

- 5.1** Pengarah Kesihatan Negeri akan menyelaras pelaksanaan rujukan pesakit daripada mana-mana hospital di bawah bidang kuasa pihak negeri terlibat kepada pakar kardiologi pediatrik sebagaimana sistem rujukan sedia ada bagi tujuan menjalani rawatan di Hospital Narayana Hrudayalaya mengikut garis panduan yang telah disediakan.
- 5.2** Pakar-pakar pediatrik kardiologi bertanggungjawab untuk mengenalpasti pesakit-pesakit jantung kongenital kanak-kanak yang memenuhi kriteria untuk rawatan pembedahan jantung di Hospital Narayana Hrudayalaya.
- 5.3** Pegawai kerja sosial perubatan bertanggung jawab menjalankan penilaian sosio ekonomi ke atas pesakit dalam kadar segera agar urusan penghantaran pesakit dapat berjalan lancar. Segala implikasi sumber perlu dikenalpasti agar memudahkan perancangan penghantaran pesakit.
- 5.4** Pakar pediatrik kardiologi perlu memantau keberkesanan pelaksanaan program ini, dan mengumpulkan maklumat/statistik mengenai rawatan pembedahan di Hospital Narayana Hrudayalaya ini. Laporan berkala perlu dikemukakan kepada Bahagian Perkembangan Perubatan bagi tujuan pemantauan.

6. TARIKH BERKUATKUASA

Arahan ini berkuatkuasa mulai dari tarikh surat ini dikemukakan.

7. PERTANYAAN

Sebarang pertanyaan boleh dikemukakan kepada;

Pengarah

Bahagian Perkembangan Perubatan

Aras 7, Blok E 1, Parcel E

Pusat Pentadbiran Kerajaan Persekutuan

62590 Putrajaya

No. Telefon : 03-88831047

No. Fax : 03- 88831427

Sekian, terima kasih.

“BERKHIDMAT UNTUK NEGARA”

Saya yang menjalankan tugas,

TAN SRI DATUK DR. HJ. MOHD ISMAIL MERICAN

Ketua Pengarah Kesihatan Malaysia.

- s.k. - Ketua Setiausaha Kementerian Kesihatan Malaysia
- Timbalan Ketua Setiausaha (Kewangan)
 - Timbalan Ketua Setiausaha (Pengurusan)
 - Timbalan Ketua Pengarah Kesihatan (Kesihatan Awam)
 - Timbalan Ketua Pengarah Kesihatan (Perubatan)
 - Timbalan Ketua Pengarah Kesihatan (Penyelidikan & Sokongan Teknikal)

GUIDELINES ON THE MANAGEMENT OF CHILDREN WITH CONGENITAL HEART DISEASES FOR CARDIOTHORACIC SURGERY IN NARAYANA HRUDAYALAYA INSTITUTE OF CARDIAC SCIENCES (NH), BANGALORE, INDIA.

1. OBJECTIVE

These guidelines provide information on the selection of cases for cardiothoracic surgery at Narayana Hrudayalaya Institute of Cardiac Sciences (NH), Bangalore, India, the work process for requesting funding from the Tabung Bantuan Perubatan (TBP), and the referral process of the selected cases to NH for surgery till the patients are discharged and returned home for follow-up care.

2. BACKGROUND

The incidence of Congenital Heart Diseases (CHD) among Malaysian children is about 8 to 10 per 1,000 live births. With an average of 500,000 deliveries a year, the number of children born with CHD is about 5,000 a year, of which two-thirds will require surgical intervention. Hence the number of children requiring surgery each year is about 2,000 to 3,000.

In Malaysia, complex pediatric cardiothoracic surgeries are done only by the National Heart Institute (IJN) and two other private hospitals. Thus the waiting time for surgery may be unacceptably long for certain cases. This delay is compounded by the shortage of local pediatric cardiothoracic surgeons. Further more, the cost of cardiothoracic surgery in private hospitals is often high, thereby limiting access to such services for ordinary Malaysians. Consequently, some children have died while waiting for their surgery.

In addressing these issues, the Cabinet has decided that the government will bear the cost of cardiothoracic surgery for poor Malaysian children undergoing surgery at NH, through the Medical Assistance Fund or 'Tabung Bantuan Perubatan' (TBP).

NH is a world renowned hospital for cardiology and cardiothoracic services for adult and children afflicted with heart diseases. It has the capacity and capability to treat both local and international patients, and perform simple to complex surgeries, using advanced, high tech equipment. The hospital is well staffed with skilled specialists, paramedics and supporting clinical and non-clinical personnel.

NH has offered to perform cardiothoracic surgeries for Malaysian children at a discounted rate that is much lower than those charged by Malaysian private hospitals.

The Cabinet has agreed to allocate RM 2 million annually from the TBP to enable poor children from Malaysia to undergo the required cardiothoracic surgery in NH.

For the purpose of facilitating the surgery of CHD children at NH, NH has appointed MediAssist4U Clinic (M4U) as the local agent or facilitator. The clinic will use its teleconferencing facilities for teleconsultation with NH. The necessary arrangements for the patients and their parents / guardians to travel to India will be done by M4U as well.

3. IMPLEMENTATION PROTOCOL

3.1 PATIENT SELECTION CRITERIA

CHD children from poor families, in stable condition and have waited long for surgery are eligible to be sent to NH. The patients are from MOH hospitals and the selection has to be done by MOH Pediatric Cardiologists.

3.1.1 The cases to be referred to NH will be decided by MOH Pediatric Cardiologists. Generally the patients are those suffering from Chronic CHD, stable, have waited long for surgery and are fit for travel to India by air.

3.1.2 The types of cases listed in Appendix 1 may be used as a guide.

3.2 PREOPERATIVE ASSESSMENT

The attending Pediatric Cardiologist will be responsible for assessing and deciding on the suitability of the patients to have surgery in NH.

3.2.1 Clinical condition

3.2.1.1 The patient should be free from any infection.

3.2.1.2 The patient should be optimised as far as possible.

3.2.1.3 Selected cases should be fit for air travel and of favourable prognosis.

3.2.2 An eligibility assessment will be carried out by a committee before the patient can be sent to NH.

3.2.2.1 The selected cases will be assessed and endorsed by the Hospital Technical Committee, Hospital Director, Head of Department of Pediatric Cardiology / or Cardiothoracic Surgeon. Cases which fulfill the selection criteria will be recommended for referral to NH for surgery.

3.2.2.2 Cases needing financial assistance from the TBP will be referred to the Hospital Medical Social Worker who will perform the socio-economic status assessment (using Form A – patient biodata and Form B – screening for socio-economic status) as in Appendix 2.

3.2.2.3 The work process for the referral of cases to NH is displayed in Appendix 2.

3.2.3 TBP Assessment

The cases will be assessed according to TBP requirements, whereby the Technical Cardiothoracic Assessment Committee of the TBP in the Ministry of Health (MOH) will scrutinize each application for surgery in NH. The Committee's recommendations will be forwarded to the Director General of Health, MOH, who will in turn seek the final approval of the Secretary- General of the MOH to use TBP to fund the surgery in NH.

3.3 PATIENT REFERRAL TO NH

Following approval, the patients will be seen, teleconsulted with NH and counseled by M4U prior to traveling to India.

In the event of NH refusal to undertake the surgery for any reasons, the patient will be referred back to the MOH hospital at no cost.

M4U will make all the arrangements required to enable the selected patients to travel to India for surgery, once agreed by NH through the videoconferencing session between them.

3.4 ROLES OF MEDIASSIST4U

M4U is responsible for the following:

Clinical Screening

3.4.1 A referral letter will be given by the MOH Pediatric Cardiologist and brought along by the patients to M4U for the purpose of teleconsultation with NH.

3.4.2 Teleconference – M4U will arrange for the teleconsultation session with NH to ascertain the suitability of the patients for surgery in India.

- 3.4.3 The clinical information of the patients will be sent over to NH and discussed with NH's Pediatric Cardiologists and Pediatric Cardiothoracic surgeons.
- 3.4.4 NH's specialists will then make the decision whether to accept the patients into their Operating Lists.
- 3.4.5 Preoperative counseling will be provided by M4U to the patients and/or family members once the case is accepted by NH.

Travel Arrangements

- 3.4.6 M4U will undertake all the required travel arrangements to India for the patient and a parent / guardian, which include the passports, visas, return flight tickets and travel insurance.
- 3.4.7 M4U will provide a patient ambassador to accompany a group of patients and their parents / guardians to India and to safe-keep their passports and flight tickets throughout the journey.
- 3.4.8 M4U will ensure the smooth management of these patients, especially their travel to NH.
- 3.4.9 Upon arrival at the airport in Bangalore, India, NH staff will receive them and provide a suitable means of transport to and from NH hospital.
- 3.4.10 NH will be responsible for the welfare and care of the patients and their accompanying parents / guardians throughout their stay in the hospital till their discharge and return home. Upon discharge and return, M4U will meet them at the airport and make the necessary transport arrangement to send them home.

Miscellaneous

- 3.4.11 In the event of death, NH together with M4U will make the necessary arrangements to bring the body and accompanying parent / guardian home at no additional cost.

3.4.12 Invoice of the total cost incurred by each case, pegged at RM 10,000.00 (for the cost of surgery, food and lodging for the patient and a parent / guardian) will be issued by NH. An additional RM 4,900.00 per case will be paid to M4U as costs for return flight tickets, visas, passports, travel insurance and other arrangements. The invoice will be submitted to TBP secretariat by M4U after the patient has completed the surgery and returned home. TBP will then make the payment to M4U.

3.5. POST OPERATIVE CARE AND FOLLOW-UP

The patients who are fit to be discharged from NH will travel home by air. The return journey will be arranged by NH/ M4U. NH will send the patients and accompanying parents / guardians to the airport by an appropriate means of transport.

NH will provide the patient with a referral letter to the MOH Pediatric Cardiologist, containing details of the surgery done, post operative care and follow-up plans.

The patients and parents will be met at the airport by M4U and the necessary means of transport will be arranged for them to return home.

All follow-up care will be undertaken by MOH Pediatric Cardiologists.

4. CONTRACT AGREEMENT

To ensure the success of this program a contract agreement will be signed between MOH, NH and M4U outlining the roles and responsibilities of each party.

5. ENQUIRY

Any enquiries on these guidelines should be referred to:

Director

Medical Development Division

Ministry of Health

Level 7, Block E -1, Parcel E,

Federal Government Administrative Complex

62590 Putrajaya.

Tel 03-88831046, Fax: 03-88831105

Examples of chronic cases to be referred to NH for surgery (subject to the decisions by MOH Pediatric Cardiologists)

1. Duct Dependent lesions;
 - Acyanotic duct dependent lesions
 - Severe Coarctation of Aorta
 - Interrupted Aortic Arch or Hypoplastic Arch
 - Cyanotic duct dependent lesions
 - Pulmonary Atresia with or without VSD

2. Significant L- R Shunt
 - Large VSD in failure
 - Complete AVSD

3. Valvular lesion
 - Severe valvular heart lesions feasible for repair in young children

4. Cyanotic Heart Disease
 - Total anomalous pulmonary venous drainage
 - Ebstein Anomaly
 - Truncus arteriosus
 - Double Outlet Right Ventricle (DORV)
 - Tetralogy of Fallot
 - Pulmonary Atresia with VSD
 - Tricuspid Atresia with or without Pulmonary Atresia
 - Transposition of Great Arteries either with VSD or without VSD

SUGGESTED FLOW CHART FOR TBP REQUEST

