



Ministry of Health Malaysia
Pharmaceutical Services Programme

DIARI UBAT TALASEMIA

THALASSAEMIA MEDICATION DIARY



PENGENALAN / INTRODUCTION

Memahami Talasemia

Talasemia ialah penyakit darah yang diwarisi. Penyakit ini menjejaskan penghasilan hemoglobin normal yang mencukupi untuk badan. Hemoglobin ialah protein dalam sel darah merah yang membawa oksigen ke seluruh badan. Apabila paras hemoglobin rendah, badan tidak mendapat oksigen yang mencukupi. Ini menyebabkan anemia, di mana seseorang kelihatan pucat, cepat letih dan lemah.

Talasemia berlaku apabila salah seorang ibu bapa atau kedua-duanya mewariskan gen yang tidak normal kepada anak. Pesakit talasemia dibahagikan kepada dua kumpulan utama berdasarkan keperluan transfusi darah: *Transfusion-dependent Thalassaemia* (TDT) dan *Non-transfusion Dependent Thalassaemia* (NTDT). Seseorang dengan NTDT mungkin akan berkembang menjadi TDT sepanjang hayat mereka. Sebaliknya, pesakit TDT juga boleh beralih kepada NTDT berikutan kemajuan perubatan baharu.

Understanding Thalassaemia

Thalassaemia is an inherited blood disorder that affects the body's ability to make enough healthy haemoglobin – the protein in red blood cells that carries oxygen around the body. When haemoglobin levels are low, the body does not get enough oxygen. This causes anaemia, which can make a person look pale, tired or weak.

Thalassaemia happens when one or both parents pass down an altered gene that affects haemoglobin production. A person with thalassaemia can be categorised into two groups based on blood transfusion requirements: transfusion-dependent thalassaemia (TDT) and non-transfusion dependent thalassaemia (NTDT). A person with NTDT may progress to become TDT in their lifetime, or vice versa due to new medical advances.

Jenis-jenis Talasemia

1. Pembawa Talasemia

Pembawa talasemia mewarisi satu gen talasemia daripada salah seorang ibu bapa. Kebanyakan pembawa tidak menunjukkan gejala atau hanya mengalami anemia ringan. Rawatan atau transfusi darah tidak diperlukan, tetapi penting untuk mengetahui status pasangan/bakal pasangan pembawa talasemia sebelum merancang keluarga.

2. *Non-transfusion Dependent Thalassaemia* (NTDT)

Pesakit NTDT mempunyai anemia tahap sederhana dan tidak memerlukan transfusi darah secara berkala. Namun, transfusi mungkin diperlukan semasa sakit, hamil, atau semasa tempoh tumbesaran. Selepas satu jangka masa, zat besi berlebihan masih boleh terkumpul dalam badan walaupun tanpa transfusi. Pemeriksaan berkala dan dalam kes tertentu, *Iron Chelator* diperlukan untuk kekal sihat. Doktor akan memberikan nasihat untuk pengurusan rawatan yang terbaik.

3. *Transfusion-Dependent Thalassaemia* (TDT)

Pesakit TDT memerlukan transfusi darah secara berkala setiap 6-8 minggu sepanjang

hayat. Transfusi darah membantu mengekalkan hemoglobin pada bacaan yang selamat supaya tubuh membesar dan berfungsi secara normal.

Types of Thalassaemia

1. Thalassaemia Carrier

Thalassaemia carrier carries one altered gene from only one of your parents. Most people have no symptoms or only mild anaemia. No transfusion or treatment is needed, but it's important to know your partner's status before having children.

2. Non-Transfusion Dependent Thalassaemia (NTDT)

Patient with moderate anaemia but do not need regular blood transfusions. However, sometimes transfusions are needed during illness, pregnancy or growth spurts. Over time, extra iron can build up in the body, even without transfusions. Regular check-ups and in some cases, iron chelators are needed to stay healthy. Your doctors will advise you on the best treatment management for you.

3. Transfusion-Dependent Thalassaemia (TDT)

Patient with Transfusion-Dependent Thalassaemia will need regular blood transfusions every 6- 8 weeks throughout life. Blood transfusions help to maintain haemoglobin at safe levels so the body can grow and function normally.

Pilihan Rawatan

Sekiranya tiada pilihan untuk sembuh dengan pemindahan *stem cell transplant*, maka rawatan utama bagi pesakit TDT ialah transfusi darah secara berkala dan terapi *Iron Chelator*. Perkembangan perubatan terkini merangkumi rawatan seperti terapi gen serta rawatan yang sedang dikaji. Namun begitu, rawatan-rawatan ini belum tersedia untuk semua pesakit, dan ada yang masih dalam peringkat kajian klinikal.

1. Transfusi Darah Berkala

Transfusi darah membantu mengekalkan bacaan hemoglobin pada tahap selamat supaya badan mendapat oksigen yang mencukupi dan mencegah daripada mendapat komplikasi kesihatan yang lain.

2. Iron Chelators

Setiap beg darah yang diterima melalui transfusi mengandungi kira-kira 200 mg zat besi yang terkumpul dalam badan. Transfusi yang berulang akan menyebabkan keadaan yang dipanggil sebagai zat besi yang berlebihan (*iron overload*). Situasi ini boleh merosakkan jantung, hati dan kelenjar hormon, lalu menyebabkan komplikasi kesihatan yang serius. *Iron Chelators* berfungsi membuang zat besi yang berlebihan ini. Terdapat tiga (3) jenis *Iron Chelators* iaitu:

Deferoxamine - ubat diberi melalui suntikan di bawah kulit

Deferiprone - ubat oral

Deferasirox - ubat oral

Pengambilan ubat secara konsisten adalah penting untuk membantu melindungi organ badan dan memastikan anda kekal sihat.

Treatment Options

If there is no option for a cure with stem cell transplant, then the mainstay of treatment

for TDT patients are regular blood transfusion and iron chelation therapy. Other treatment options include transformative options such as gene therapy/gene editing; and novel therapy that can treat the disease. However, these treatment options are not readily available nor suitable for everyone. Some are still under clinical trials.

1. Regular Blood Transfusions

Blood transfusions help keep haemoglobin at a healthy level, so the body gets enough oxygen and to prevent other health complications.

2. Iron Chelation Therapy

Every bag of blood transfused deposited approximately 200mg of iron in the body. Repeated blood transfusions cause harmful iron to build up in the body, a condition called iron overload. Too much iron can harm the heart, liver and glands resulting in serious health complications to the person. Iron chelators remove extra iron. There are three (3) types of iron chelators

Deferoxamine - injection using a subcutaneous pump

Deferiprone - oral

Deferasirox – oral

Taking your medicine regularly helps protect your organs and keeps you feeling well.

Hidup Sihat dengan Talasemia

Pesakit talasemia boleh menjalani kehidupan yang panjang, sihat dan aktif dengan rawatan yang betul. Penjagaan sendiri ialah kunci utama untuk kekal sihat: ambil ubat secara teratur, hadir sesi janji temu susulan, uruskan emosi dan tekanan dengan baik, amalkan gaya hidup sihat dan pemakanan yang seimbang. Berbincanglah dengan pasukan rawatan jika anda memerlukan sokongan.

Living Well with Thalassaemia

With the right care, people with thalassaemia can live long, healthy, and active lives. Empowering yourself such as taking your medications, attending follow-up visits, regulating your emotions and maintaining a healthy lifestyle are key to keeping well. Speak to your treatment team if you need support.

Tentang Diari ini

Diari ini disediakan untuk membantu anda memahami dan menguruskan penyakit serta ubat-ubatan talasemia.

Nota: Maklumat dalam buku ini adalah panduan umum. Pelan rawatan setiap individu adalah berbeza. Sentiasa ikut nasihat doktor, ahli farmasi dan pasukan rawatan anda.

About This Diary

This diary is intended to help you understand, manage your condition and medications.

Note: The information contained serves as a general guide. Your treatment plan is unique to you. Always follow the advice of your doctor, pharmacist and healthcare team.

MAKLUMAT PERIBADI / *PERSONAL DETAILS*

SILA LETAK
GAMBAR
ANDA

Nama/*Name*: _____

No. KP/ *IC*: _____

Tarikh Lahir/ *Date of Birth*: _____

No. Telefon/ *Telephone*: _____

Jika berlaku kecemasan, sila hubungi/ *In case of emergency, please contact*:

Nama/*Name*: _____

Hubungan/ *Relationship*: _____

No. Telefon/ *Telephone*: _____

MAKLUMAT ASAS/ BASIC DETAILS

Mutasi / Profil DNA talasemia anda:

Your thalassaemia mutation / DNA profile: _____

Kumpulan darah/ *Blood group:* _____

Fenotip sel darah merah

Red blood cell phenotype: _____

Antibodi sel merah Ya / Tidak
Red cell antibodies *Yes / No* _____

Splenectomy Ya / Tidak ; pada(jika ya)
Splenectomy *Yes / No ; when(if yes)* _____

Cholecystectomy Ya / Tidak
Cholecystectomy *Yes / No*

Masalah jantung Ya / Tidak
Heart problems *Yes / No*

Jangkitan hepatitis C Ya / Tidak
Hepatitis C infection *Yes / No*

Jangkitan hepatitis B Ya / Tidak
Hepatitis B infection *Yes / No*

Kencing manis Ya / Tidak
Diabetes *Yes / No*

Hipotiroid Ya / Tidak
Hypothyroidism *Yes / No*

Hipoparatiroid Ya / Tidak
Hypoparathyroidism *Yes / No*

Hypogonadism Ya / Tidak
Hypogonadism *Yes / No*

Osteoporosis Ya / Tidak
Osteoporosis *Yes / No*

Penyakit lain/
Other medical conditions:

Alahan/ Allergic to:

SALASILAH KELUARGA SAYA / *MY FAMILY TREE*

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Catat masa pengambilan ubat anda/ *Write down the time when you take your medicine.*

Bulan/ *Month*: _____ Tahun/ *Year*: _____

| <i>Hari/ Day</i> | Masa pengambilan/ <i>Time to take</i> <i>Iron Chelators / Iron chelators</i> | | | | | <i>Catatan/ Notes</i> |
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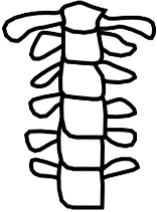
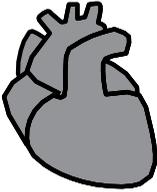
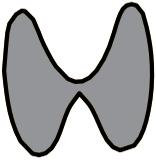
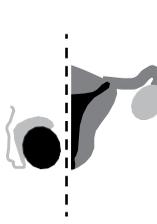
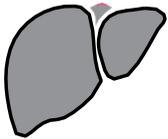
DIARI PENGAMBILAN UBAT / *MEDICATION DIARY*

Catat masa pengambilan ubat anda/ *Write down the time when you take your medicine.*

Bulan/ *Month*: _____ Tahun/ *Year*: _____

| Hari/ Day | Masa pengambilan/ <i>Time to take</i> <i>Iron Chelators / Iron chelators</i> | | | | | Catatan/ <i>Notes</i> |
|--------------|---|--------------|-------------|------|-----|--------------------------|
| | Deferasirox | Deferoxamine | Deferiprone | | | |
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KOMPLIKASI ZAT BESI BERLEBIHAN / COMPLICATIONS OF IRON OVERLOAD

| Zat besi yang berlebihan boleh mengakibatkan/ <i>Iron overload can lead to:</i> | | | | |
|---|---|---|---|--|
|  |  |  |  |  |
| Penyakit tulang (termasuk osteoporosis) | Hipertensi pulmonary | Hipotiroid | <i>Hypogonadism</i> | Fibrosis dan sirosis hati |
| <i>Bone disease (including osteoporosis)</i> | <i>Pulmonary hypertension</i> | <i>Hypothyroidism</i> | <i>Hypogonadism</i> | <i>Liver fibrosis and cirrhosis</i> |

Sila nyatakan masalah-masalah yang sedang anda alami/
Please identify problems that you are currently having:

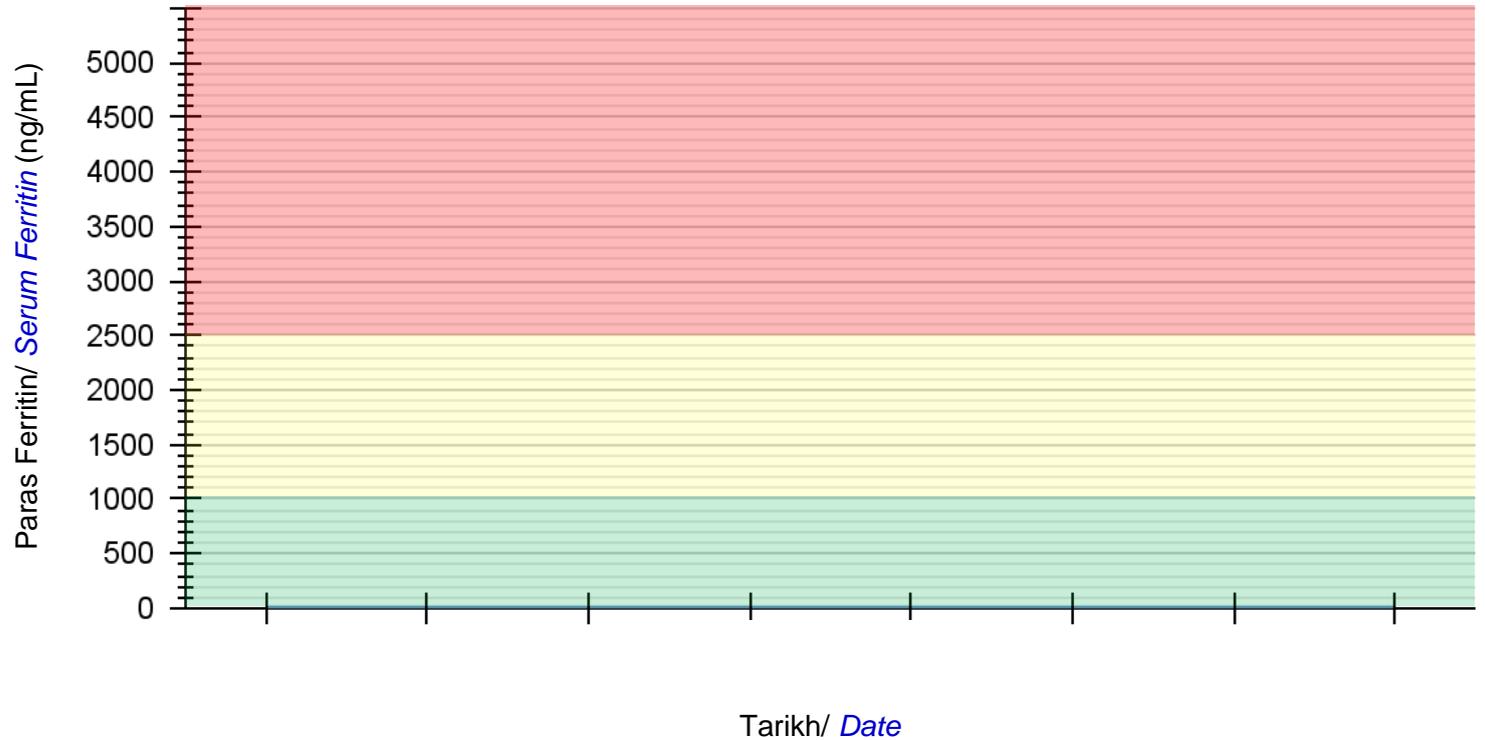
| | |
|--|---|
| | Melanin berlebihan dalam kulit/ <i>Excessive melanin in the skin</i> |
| | Kegagalan/lemah jantung/ <i>Cardiac failure</i> |
| | Sirosis/fibrosis/kanser hati/ <i>Liver cirrhosis/fibrosis/cancer</i> |
| | Kencing manis/ <i>Diabetes mellitus</i> |
| | Gangguan toleransi glukosa/ <i>Impaired GTT (Glucose Tolerance Test)</i> |
| | Osteoporosis/penyakit sendi/ <i>Osteoporosis/arthropathy</i> |

| | |
|--|---|
| | Ketidaksuburan/ <i>Infertility</i> |
| | <i>Extramedullary haematopoiesis/ Extramedullary haematopoiesis</i> |
| | Kegagalan paru-paru/ <i>Lung dysfunction</i> |
| | Masalah tiroid/ <i>Thyroid problem</i> |
| | Kegagalan tumbesaran/ <i>Growth failure</i> |

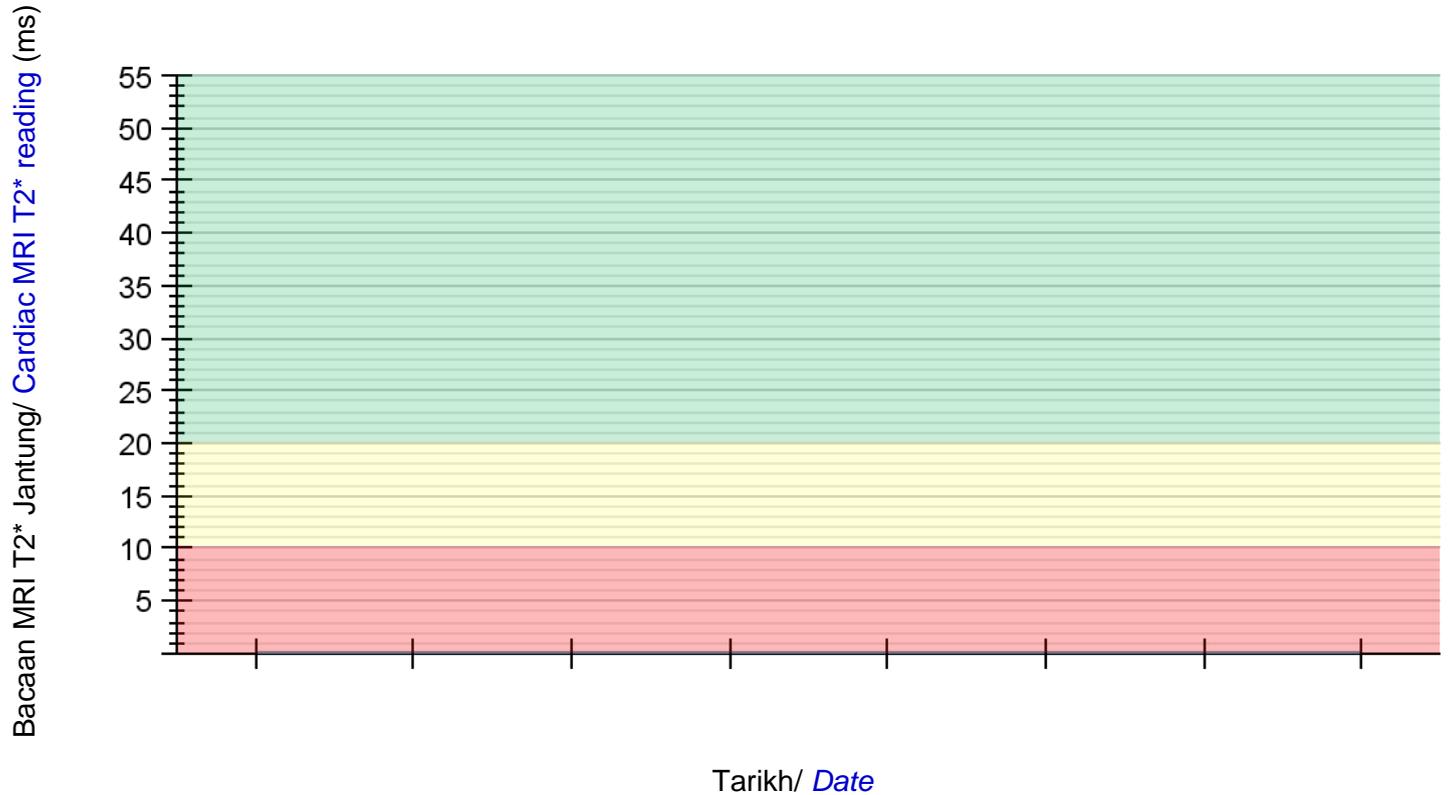
TIP PENJAGAAN DIRI/ **SELF CARE TIPS**

1. Gunakan kotak pil/ *Use a pill box*
2. Perkasakan pengetahuan anda/ *Empower yourself with knowledge*
3. Harungi kesan-kesan sampingan/ *We are fighters, fight the side effects! Pull through it*
4. Gunakan teknologi dengan bijaksana/ *Take advantage of technology*
5. Jadikan rawatan sebahagian dari rutin harian/ *Include the treatment in your daily routine*
6. Ritual penjagaan diri/ *Self care ritual*
7. Tetapkan penggera/ *Set alarm*
8. Berbincang dengan pakar perubatan anda/ *Talk openly with your healthcare provider*
9. Tetapkan matlamat dan pantau kemajuan/ *Set a target and track your progress*
10. Wujudkan sistem sokongan/ *Build a support system*

Bacaan Ferritin/ *Ferritin Trend*



Bacaan MRI T2* Jantung/ *Cardiac MRI T2* reading*



Beban Zat Besi Dalam Hati/ *Liver Iron Concentration*



Tarikh/ *Date*



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