THE COVID–19 PANDEMIC AND HAEMOGLOBIN DISORDERS

A TIF-proposed Haemoglobinopathy Patient Pathway

Recommendations for Day Care Centres, Units and Clinics treating patients with thalassaemia and sickle cell disease

Keeping our patients healthy and safe from COVID-19
WHY AND WHAT CHANGES MUST BE CONSIDERED

The proposed Patient Care Pathway requires changes to be made during the outbreak of COVID-19 in the admittance of patients to haemoglobinopathy day care centres /units /clinics, with the aim to protect the individual patient, medical and other personnel as well as other patients visiting the centre/unit/clinic from possible coronavirus infection.

The two (2) major changes include:

1. Strengthening of existing, and creation of new, COMMUNICATION CHANNELS between doctors, healthcare professionals and patients;

2. Promotion of a specific PATIENT PATHWAY to be as meticulously as possible followed in order to obtain access to, move within and exit day care centres/units/clinics, with particular attention to creation of dedicated, closed-off, disinfected areas for treating cases suspected or diagnosed with COVID-19 and;

   i. Reforming CARE and MONITORING PROTOCOLS for clinical management, to include additional information/questions related to COVID-19 pandemic and;

   ii. Re-arrangement, based on prioritization and individual patient needs of MONITORING TESTS (e.g. radiological, laboratory etc).
COMMUNICATION CHANNELS

- Communication Channels & Tools that will facilitate information sharing from PATIENTS/ CAREGIVERS → HEALTHCARE PROFESSIONALS (A & B below)

Aim: To ensure appropriate responses to queries, timely reporting of symptoms relating to COVID-19 and to provide advice on necessary distancing or other measures that need to be taken.

A. DEVELOPMENT OF SPECIFIC CHANNELS & TOOLS:

- HELPLINE
- EMAIL
- EMERGENCY 24 HOUR TELEPHONE NUMBER

B. FOLLOW PROTOCOL FOR ANSWERING ENQUIRIES:

HAEMOGLOBINOPATHY CENTRES / UNITS / CLINICS
ENQUIRY PROTOCOL DURING COVID-19 PANDEMIC

IS THE ENQUIRY URGENT?

Yes
- MEDICAL STAFF TO PREPARE THE RESPONSE
- INFORM THE ENQUIRER OF RESPONSE (BY TELEPHONE, SMS OR EMAIL)

No
- RESPONSE CAN BE DELAYED BUT BE ANSWERED WITHIN THE DAY (PREFERABLY WITHIN 2-4 HOURS) BY AN EXPERIENCED NURSE (AFTER CONSULTATION WITH MEDICAL DOCTORS, IF NEEDED)

IN EMERGENCIES, PATIENTS / CAREGIVERS SHOULD CALL THE PROVIDED EMERGENCY TELEPHONE NUMBER

A FEEDBACK FORM SHOULD BE AVAILABLE (EITHER PRINTED OR IN ELECTRONIC FORMAT) SO PATIENT SATISFACTION ON THE FLOW OF INFORMATION IS RECORDED

This can only be assessed if the operator is an experienced nurse or doctor.
- Communication Channels & Tools that will facilitate information sharing from HEALTHCARE PROFESSIONALS → PATIENTS/ CAREGIVERS (C below)

Aim: To provide information on latest national COVID-19 pandemic updates (e.g. no. of cases, government measures, hospital policies etc) to haemoglobinopathy patients.

C. MAINTAIN REGULAR FLOW OF QUALITY INFORMATION TO PATIENTS:

CREATE A GROUP OF MEDICAL DOCTORS WITH A ROTATION SYSTEM (TO DISTRIBUTE WORKLOAD)

ISSUE A DAILY BULLETIN ON THE PROGRESS OF THE EPIDEMIC

PUBLISH ON CLINIC BULLETIN BOARD

PROVIDE TO NATIONAL THALASSAEMIA ASSOCIATION (WHERE IN EXISTENCE)

If a National Thalassaemia Association does not exist, the local Thalassemia Association should be informed.

If no local Thalassaemia Association exists, make use of contact details on medical file in line with national data protection policies.

For example, a copy of the daily Ministry of Health announcement regarding COVID-19.
PATIENT CARE PATHWAY

- Any visit to the day care centre/ unit/ clinic should be **APPOINTMENT – BASED ONLY** and booked in advance via telephone or wherever available online appointment systems.
- The day care centre/ unit/ clinic is advised to carry out a **2-STEP TRIAGE** (as described in the Pathway diagrams below) before any patient enters the facility.
Haemoglobinopathy Patient Pathway during COVID-19 Outbreak (Not Transfusion Related)

**START:** Patient calls day centre to report feeling unwell (transfusion not due soon)

- Discuss symptoms with doctor over the phone

Is it necessary for the patient to visit the day care centre for further examination?

- Yes!
  - On arrival at the day care centre, a separate TRIAGE area, outside the hospital / clinic / centre should be available (see role of triage below)

  - Provide advice over the telephone

- No

Follow national guidelines for suspected COVID-19 incidents (see proposed testing algorithm)

Does the patient have COVID-19 related symptoms?

- Yes!
  - See Transfusion-related Pathway!

- No

Advise patient to self-isolate until COVID-19 results are confirmed

- If transfusion appointment comes before COVID-19 test results

Do the tests confirm COVID-19?

- No

  - Refer patient to COVID-19 hospital unit & maintain communication with medical personnel for thalassaemia-related aspects of treatment (transfusions during the period of COVID-19 infection should take place at the COVID-19 hospital unit)

- Yes!

  - Permit admission to day care centre for further medical examination in 'Isolation Room'

  - Provide patient with relevant medical advice

It is advisable to follow the International Guidelines for the Clinical Management of Transfusion Dependent Thalassaemia (TDT), Non-Transfusion Dependent Thalassaemia (NTDT) and Emergency Care, compiled by International Experts in the field and published by TIF, wherever possible: Available at www.thalassaemia.org.cy
TRIAGE AREA

- **SCREENING** will be undertaken to grant permission for entering the day care centre / unit / clinic.
- This will be done by the **TRIAGE NURSE**, who wearing appropriate personal protective equipment (for more information see below) will ask a series of questions (as per national guidelines for COVID-19).
- The patient’s Temperature, Pulse, Blood Pressure, Pulse Oximetry and Respiratory Rate will be checked.
- **FOR PATIENTS WITH HAEMOGLOBINOPATHIES (THALASSAEMIA AND SICKLE CELL DISEASE), HAEMOGLOBIN LEVEL SHOULD ALSO BE CHECKED.**
- If any COVID-19 symptoms are present (high temperature, dry cough etc) the triage nurse will consult with the treating physicians to decide granting admission to the day care centre / unit / clinic.
- If admittance is permitted, the patient should be taken to the ‘**ISOLATION ROOM**’ where he/she will receive the medical care required by doctors and nurses wearing appropriate personal protective equipment (for more information see below)

**Isolation Room**: Haemoglobinopathy day care centre / units / clinics should designate a specific, dedicated room within the centre / unit / clinic which will be used to provide medical care to haemoglobinopathy patients who are suspected or a positive for COVID-19. This room should ideally have a separate entrance / exit to the rest of the centre / unit / clinic so as to limit contact with other patients thus preventing transmission of COVID-19. The room should be disinfected regularly.
FOR AN INDIVIDUAL PATIENTS WITH THALASSAEMIA OR SICKLE CELL DISEASE WITH SYMPTOMS RELATED TO CORONAVIRUS INFECTIONS RUN TESTS FOR COVID-19 AND IN PARALLEL RUN TESTS FOR OTHER COMMON FLU VIRUSES

CORONAVIRUS INFECTIONS MAY CO-EXIST WITH OTHER FLU VIRUSES IN THE SAME INDIVIDUAL

NASOPHARYNGEAL SAMPLES & RNA TESTING ARE CONSIDERED THE MOST APPROPRIATE.

COVID-19 RNA TESTING SHOULD BE PERFORMED AT ONE OF THE REFERENCE LABORATORIES (ASSIGNED BY THE NATIONAL HEALTH AUTHORITIES)

IF NEGATIVE TO ALL TESTING, THE INDIVIDUAL SHOULD PRACTISE SOCIAL DISTANCING / STAY AT HOME FOR 14 DAYS (AS ALSO RECOMMENDED BY NATIONAL HEALTH AUTHORITIES AND WHO)

IF POSITIVE TO COVID-19 TESTING, THE LABORATORY SHOULD REPORT THE RESULTS TO NATIONAL HEALTH AUTHORITIES, WHO IN TURN SHOULD INFORM THE TREATING PHYSICIAN AND FOLLOW NATIONAL GUIDELINES FOR MONITORING AND/OR TREATING COVID-19, AS PER NATIONAL PROTOCOLS

IF POSITIVE TO ANY OTHER THAN COVID-19 VIRUSES, TREATMENT AND CARE IS PROVIDED AS APPROPRIATE BY TREATING PHYSICIANS

THE HAEMOGLOBINOPATHY TREATING PHYSICIAN SHOULD ALWAYS PROVIDE THE PATIENTS’ FULL MEDICAL HISTORY AND MAINTAIN VERY CLOSE CONTACT WITH THE MEDICAL PERSONNEL IN ANY OF THE COVID-19 UNITS OR CLINICS THAT THE PATIENT IS REFERRED TO, ACCORDING TO NATIONAL GUIDELINES
MONITORING TESTS

- Full blood count, pre-transfusion haemoglobin levels and ferritin tests should continue as usual (in accordance to the precautions outlined in the Haemoglobinopathy Patient Pathways, see pages 5 & 6) for the duration of the COVID-19 epidemic.
- Annual routine monitoring tests (i.e. MRI, Ferriscan, DEXA, Ophthalmology & Audiology) for patients who have low iron load and are stable should be postponed until after the end of the epidemic, unless the treating physician advises otherwise.

NO MEDICATION SHOULD BE DISCONTINUED WITHOUT INSTRUCTIONS / CONSENT OF THE TREATING PHYSICIAN

Ibuprofen & COVID-19: Concerns have been raised on the impact of taking ibuprofen to relieve COVID-19 symptoms. Until more evidence is available, patients are advised to consider other medications, such as paracetamol, and talk to their doctors. Always be mindful of allergies before taking any medication.

Blood Groups & COVID-19: Susceptibility to the SARS-CoV-2 virus (responsible for COVID-19) by any particular blood group has not been scientifically proven. Evidence and published literature show that COVID-19 is distributed across blood groups and no blood group has an exceptional vulnerability to the virus.

RESOURCES REQUIRED

Communication Channels:
- Helpline – telephone devices
- Set up a separate email address
- Emergency telephone number

Patient Pathway:
- Designated triage area outside the clinic (no connection with the clinic)
- Separate, isolation room for patients with COVID-19 who require transfusions

Equipment for healthcare professionals:
- Personal protective equipment, including but not limited to gloves, gowns/aprons, goggles or face shields, facemasks and respirators¹.

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HOW TO STAY SAFE DURING COVID-19

- Follow the advice given by your National Health Authorities and the World Health Organization (see graphics below)

- If you feel unwell, contact your treating physician / team as soon as possible

- If you think you have COVID-19, DO NOT GO TO THE DAY CARE CLINIC!!! This will result in possibly infecting doctors, nurses and other patients. Call ahead to make an appointment.

- Refer to TIF’s publications regarding COVID-19 available at https://thalassaemia.org.cy/covid-19-pandemic/tif-material-on-covid-19/
How to Wash Your Hands
The 12 Step Checklist

Cleaning Agents: Soap & Water.
Duration: 40 – 60 Seconds.

1. Wet your hands with water.
2. Apply soap to cover all of the surfaces of your hands.
3. Rub your hands, palm to palm.
4. Move your right hand over your left hand with interlaced fingers, and vice versa.
5. Ensure your hands are palm to palm and your fingers are interlaced.
6. The backs of your fingers should be matched to your opposing palms with your fingers interlocked.
7. Rotationally rub your left thumb in your clasped right hand and vice versa.
8. Continue rotational rubbing backwards and forwards with your clasped fingers of your right hand in your left palm and vice versa.
9. Rinse your hands with water.
10. Dry your hands thoroughly with a single use towel.
11. Use the towel to turn off the faucet.
12. Your hands are now washed correctly.
WHAT IS SOCIAL DISTANCING? \(^2\)

Social distancing measures are steps you can take to reduce social interaction between people. This will help reduce the transmission of coronavirus (COVID-19).

They are to:

1. Always keep 1 – 3 metres distance from any other person
2. Avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough
3. Avoid non-essential use of public transport when possible
4. Work from home, where possible. Your employer should support you to do this.
5. Avoid large and small gatherings in public spaces.
6. Avoid gatherings with friends and family. Keep in touch using remote technology such as phone, internet, and social media
7. Use telephone or online services to contact your doctor or other essential services

HOW TO SELF-ISOLATE \(^3\)

- Stay at home. Do not go to the day unit, work, school or public places.
- Do not use public transport or taxis. Ask friends and family or delivery services to do errands for you.
- Try to avoid having visitors at home. It is okay for friends, families and delivery people to drop off food.
- You may need to do this for up to 14 days to help reduce the possible spread of infection.

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\(^3\) [https://ukts.org/heads-up/coronavirus-information/](https://ukts.org/heads-up/coronavirus-information/)
FURTHER READING

WORLD HEALTH ORGANISATION https://www.who.int/emergencies/diseases/novel-coronavirus-2019


THALASSAEMIA INTERNATIONAL FEDERATION – RESOURCES ON COVID-19:

✓ The COVID-19 Pandemic & Haemoglobin Disorders
✓ A Useful Health & Nutrition Short Guide for the COVID-19 Pandemic

Available at https://thalassaemia.org.cy/covid-19-pandemic/tif-material-on-covid-19/

**Coming Soon**
TIF’s COVID-19 Bulletin
To be published on TIF’s website & social media
A weekly update including the latest news on scientific developments for Treatments, Vaccines, Diagnosis, and Monitoring Tests

Stay Safe – Stay Informed!

TIF COVID-19 HELP DESK & COMMUNICATION LINE

To facilitate contact with our members and patients, we have created a Help Desk & Communication Line, specifically for issues concerning the COVID-19 outbreak!

YOU CAN REACH US DIRECTLY AT TIF-COVID19@THALASSAEMIA.ORG.CY