



A PHOTOVOICE COLLECTION



LIVING WITH BREATHLESSNESS

Glimpses into Stories of Struggle, Strength, and Survival
of Those Living with Chronic Respiratory Diseases

Living with Chronic Respiratory Diseases: Project Background

The Living with Chronic Respiratory Diseases (CRDs) project began in 2024 as a participatory study led by Universiti Malaya and Universiti Putra Malaysia, in collaboration with selected primary care clinics in the Klang District, Selangor. Using Photovoice, a method that places cameras in the hands of participants, we invited individuals living with CRDs to document the moments, places, and objects that shape their breathing lives. What you see here is a curated selection, developed collaboratively with the photographers themselves.

What is Chronic Respiratory Disease?

“Chronic respiratory disease” is an umbrella term for long-term conditions such as asthma, chronic obstructive pulmonary disease (COPD), post-tuberculosis lung damage, lung cancer, and bronchiectasis. CRDs limit airflow, cause breathlessness, and may require lifelong treatment. In Malaysia, they affect an estimated one in eight adults, yet remain underdiagnosed and under-resourced.

Why does this matter?

Breath is usually silent, until it is lost. CRD steals school days, wages, and sleep, yet its human stories are rarely heard beyond the walls of health facilities. This exhibition centres those voices, revealing how environmental hazards, social support, medicine, and resilience are intertwined. We hope each image deepens public understanding and sparks action towards cleaner air, earlier diagnosis, and kinder, more empathetic care.

Hidup Bersama Penyakit Kronik Pernafasan: Latar Belakang Projek

Projek Hidup Bersama Penyakit Kronik Pernafasan (CRDs) bermula pada tahun 2024 sebagai sebuah kajian penyertaan yang diketuai oleh Universiti Malaya dan Universiti Putra Malaysia, dengan kerjasama klinik-klinik kesihatan terpilih dari Daerah Klang, Selangor. Dengan menggunakan kaedah Photovoice, iaitu teknik menggunakan kamera oleh peserta kami, kami menggalakkan individu-individu yang hidup dengan CRDs untuk mendokumentasikan detik, tempat serta objek yang membentuk kehidupan mereka. Apa yang dilihat di sini adalah gambar-gambar yang terpilih yang telah dikumpul secara kerjasama bersama para peserta kajian sendiri.

Apa itu Penyakit Pernafasan Kronik ?

“Penyakit pernafasan kronik” ialah istilah umum yang merangkumi pelbagai penyakit kronik seperti asma, penyakit paru-paru obstruktif kronik (COPD), kerosakan paru-paru selepas tuberkulosis, kanser paru-paru dan bronkiektasis. CRD mengehadkan pengaliran udara, menyebabkan kesesakan nafas dan berkemungkinan keperluan rawatan sepanjang hayat. Di Malaysia, ia dianggarkan satu daripada lapan orang dewasa mempunyai masalah ini, namun ia masih kurang didiagnosis dan sumber rawatan.

Mengapakah ini penting?

Nafas selalunya tidak kedengaran, sehingga ia hilang. CRD menyebabkan kanak-kanak tidak dapat ke sekolah, kehilangan pendapatan serta tidur, namun kisah-kisah kehidupan ini jarang didengari di luar dinding fasiliti kesihatan. Pameran ini mengetengahkan suara-suara tersebut, mendedahkan bagaimana ancaman dari alam sekitar, sokongan sosial, perubatan dan ketabahan emosi saling berkait. Kami harap setiap gambar boleh buat orang awam lebih faham, lebih peduli, dan mula bertindak untuk udara yang lebih bersih, diagnosis yang lebih awal, dan rawatan yang lebih berperihatin.

ACTIVITY LIMITATIONS AND FATIGUE

HAD AKTIVITI DAN KELETIHAN



"I clean up the yard, but when I get tired and struggle to breathe, I stop. I don't force my body."

"Saya kemas halaman, tapi bila rasa penat dan susah nak bernafas, saya berhenti. Saya tak paksa badan saya."

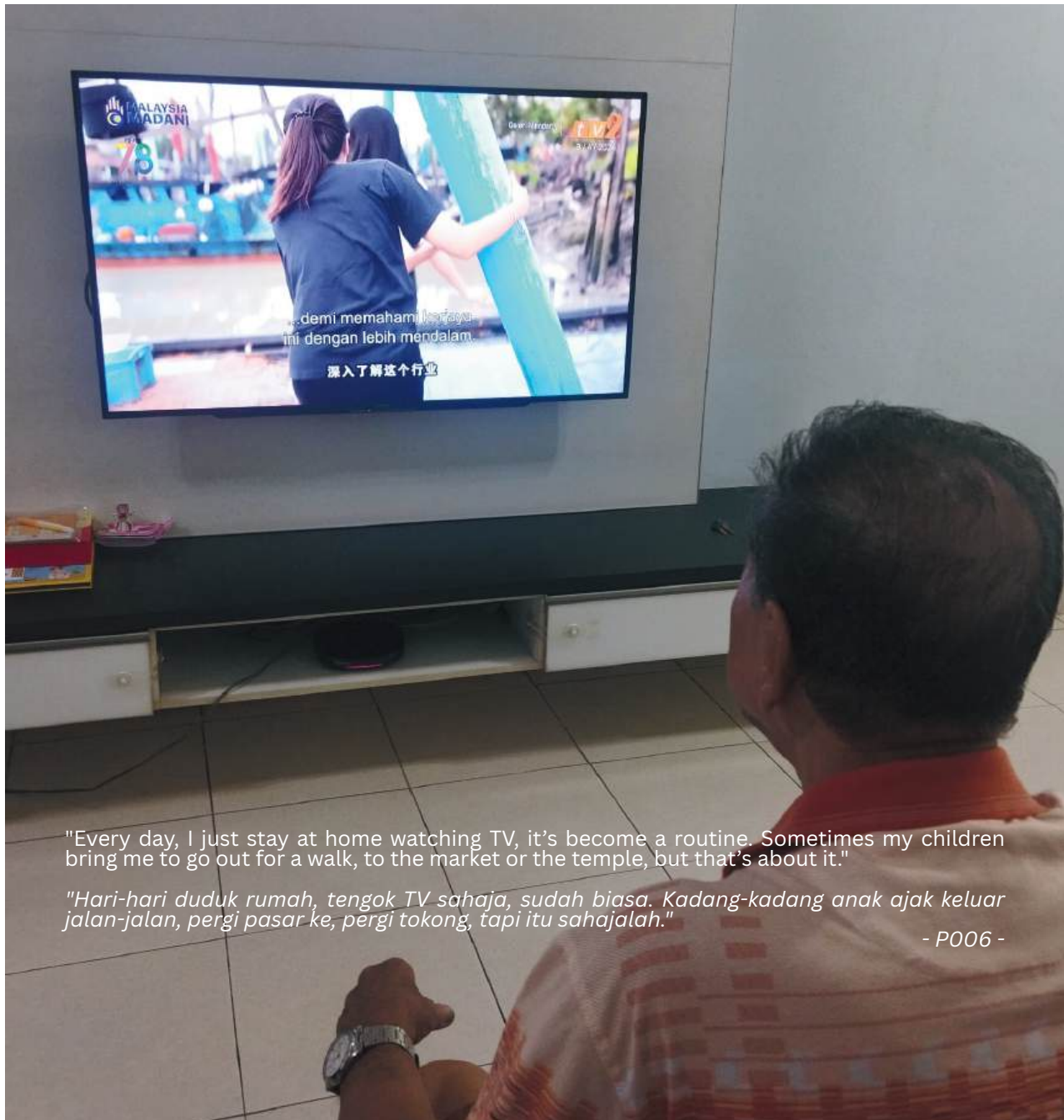
- P011 -



"When I climb the stairs, I have to hold on to something, otherwise, I'm afraid of falling, especially if I suddenly feel breathless. Climbing stairs tires me quickly, I have to stop and rest, or use my inhaler before I can continue."

"Kalau naik tangga, mesti kena pegang, kalau tak, takut jatuh terutamanya jika sesak nafas. Naik tangga cepat penat, kena berhenti dulu atau pakai ubat sedut sebelum sambung naik"

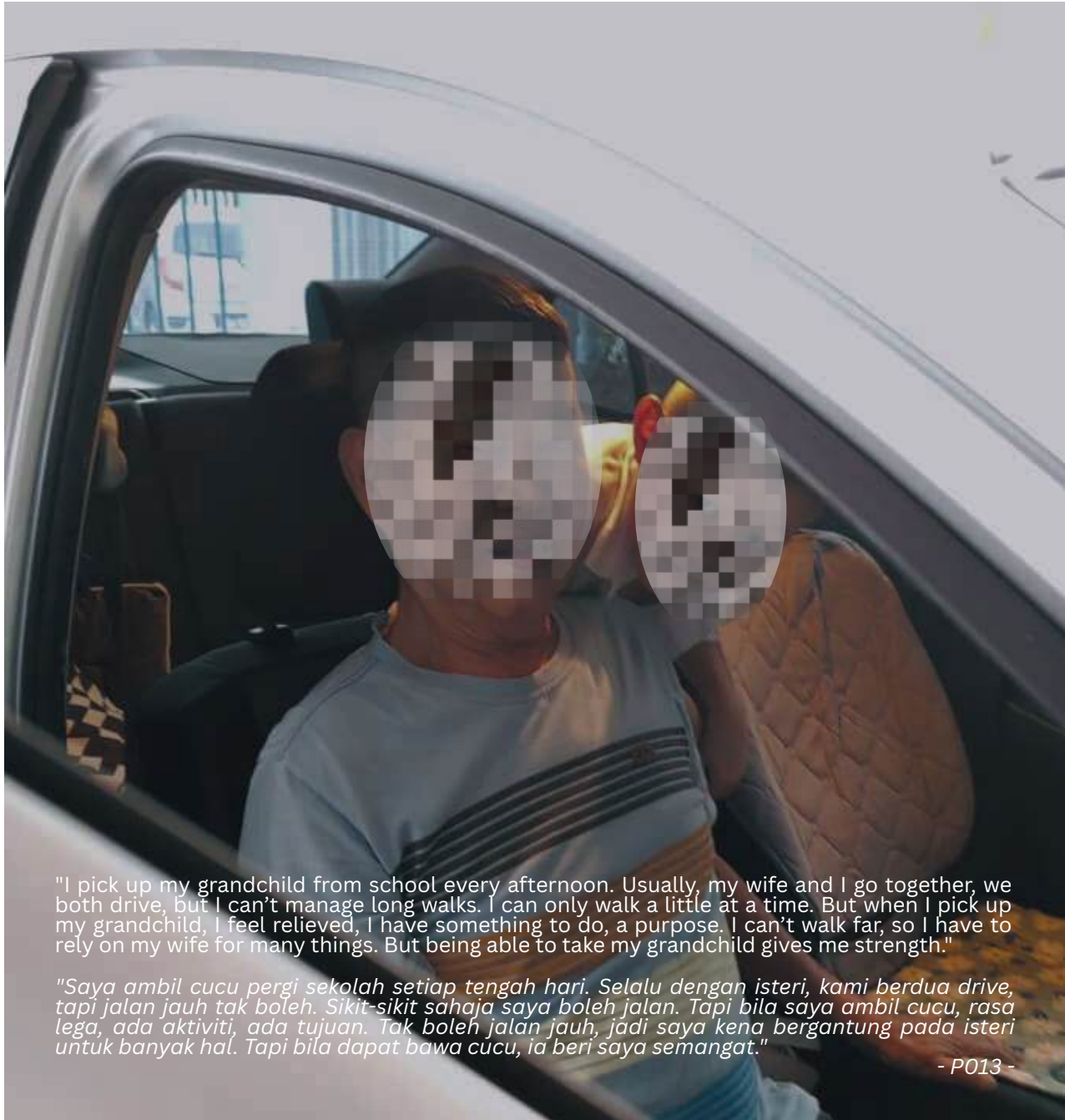
- P010 -



"Every day, I just stay at home watching TV, it's become a routine. Sometimes my children bring me to go out for a walk, to the market or the temple, but that's about it."

"Hari-hari duduk rumah, tengok TV sahaja, sudah biasa. Kadang-kadang anak ajak keluar jalan-jalan, pergi pasar ke, pergi tokong, tapi itu sahajalah."

- P006 -



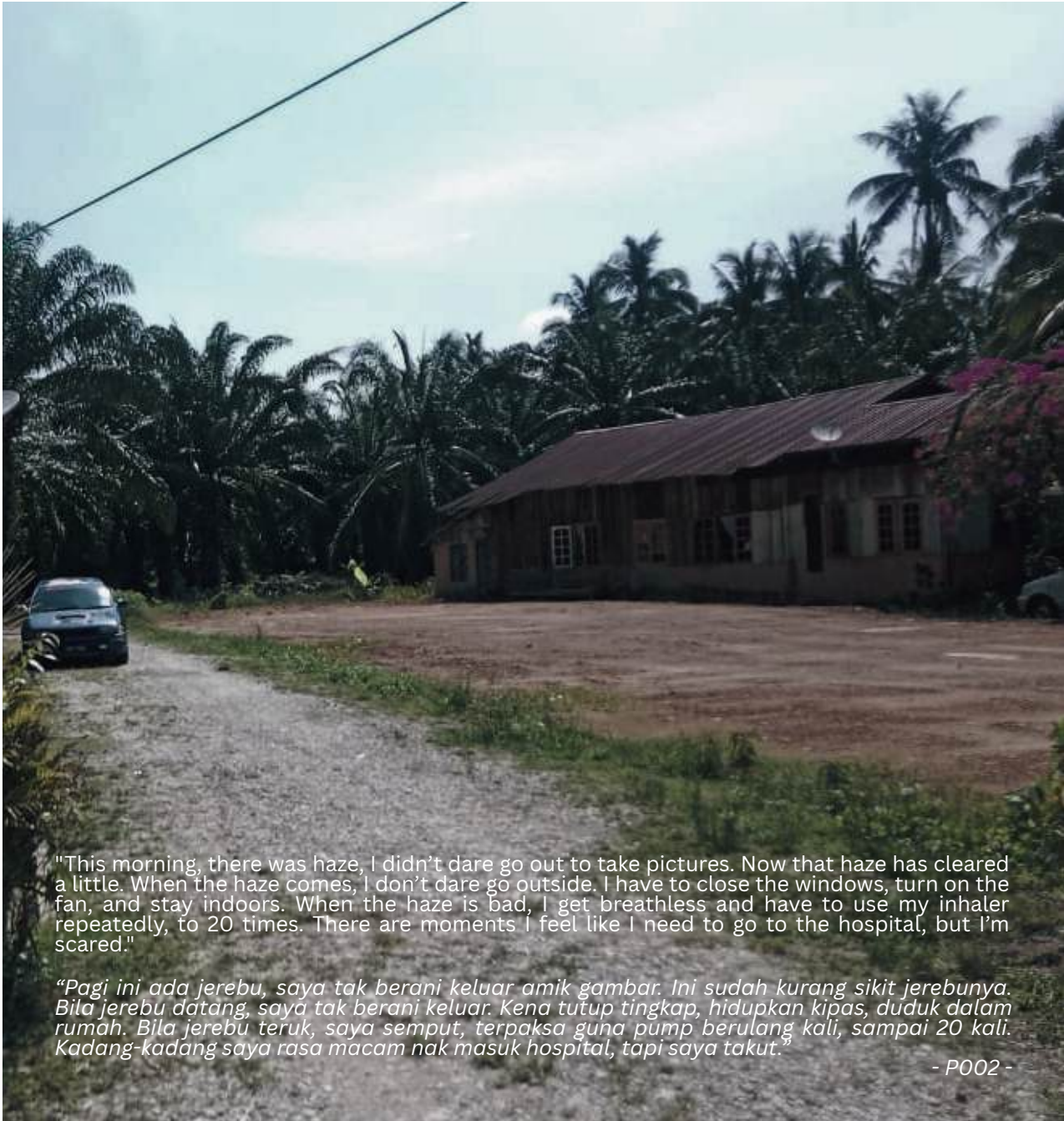
"I pick up my grandchild from school every afternoon. Usually, my wife and I go together, we both drive, but I can't manage long walks. I can only walk a little at a time. But when I pick up my grandchild, I feel relieved, I have something to do, a purpose. I can't walk far, so I have to rely on my wife for many things. But being able to take my grandchild gives me strength."

"Saya ambil cucu pergi sekolah setiap tengah hari. Selalu dengan isteri, kami berdua drive, tapi jalan jauh tak boleh. Sikit-sikit sahaja saya boleh jalan. Tapi bila saya ambil cucu, rasa lega, ada aktiviti, ada tujuan. Tak boleh jalan jauh, jadi saya kena bergantung pada isteri untuk banyak hal. Tapi bila dapat bawa cucu, ia beri saya semangat."

- P013 -

ENVIRONMENTAL TRIGGERS AND AIR QUALITY

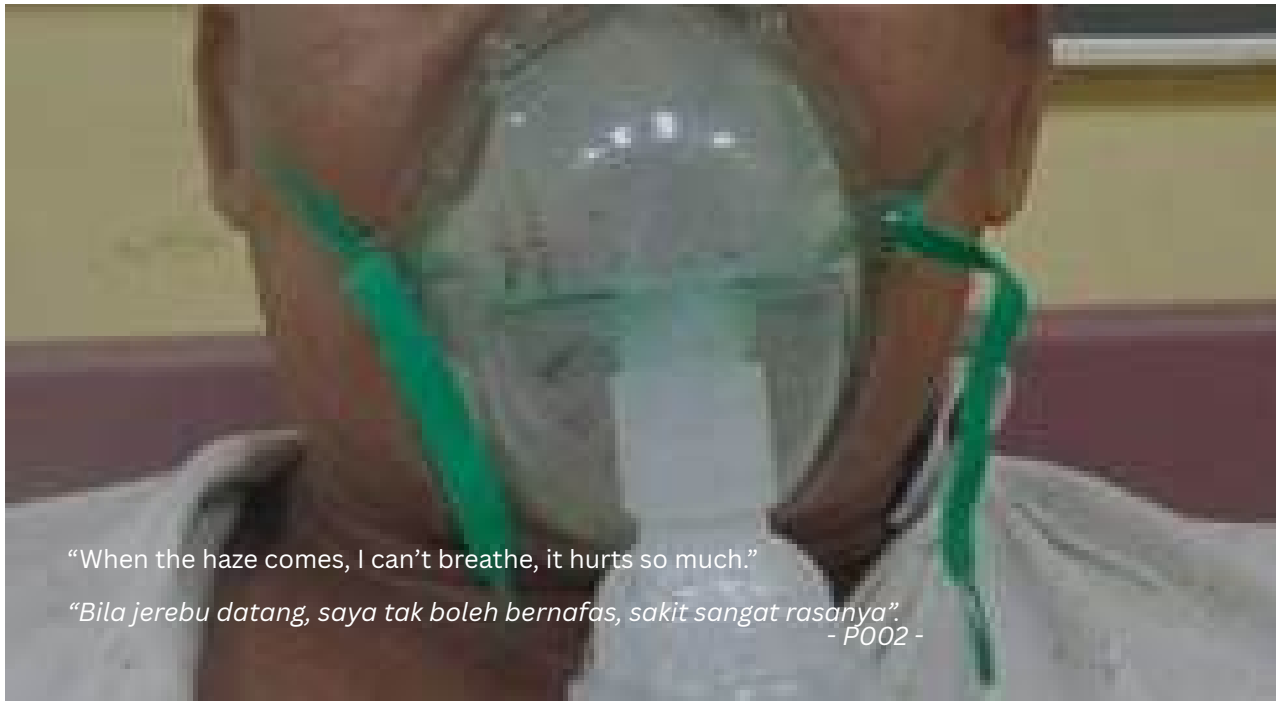
PENCETUS PERSEKITARAN DAN KUALITI UDARA



"This morning, there was haze, I didn't dare go out to take pictures. Now that haze has cleared a little. When the haze comes, I don't dare go outside. I have to close the windows, turn on the fan, and stay indoors. When the haze is bad, I get breathless and have to use my inhaler repeatedly, to 20 times. There are moments I feel like I need to go to the hospital, but I'm scared."

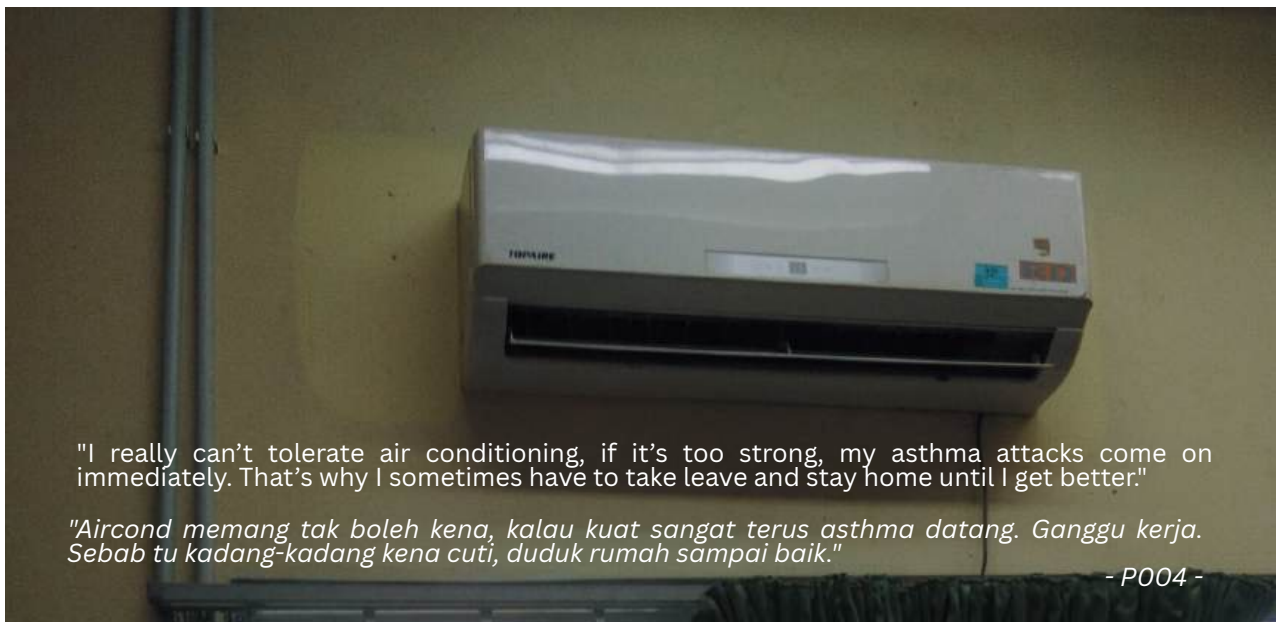
"Pagi ini ada jerebu, saya tak berani keluar amik gambar. Ini sudah kurang sikit jerebunya. Bila jerebu datang, saya tak berani keluar. Kena tutup tingkap, hidupkan kipas, duduk dalam rumah. Bila jerebu teruk, saya semput, terpaksa guna pump berulang kali, sampai 20 kali. Kadang-kadang saya rasa macam nak masuk hospital, tapi saya takut."

- P002 -



"When the haze comes, I can't breathe, it hurts so much."

"Bila jerebu datang, saya tak boleh bernafas, sakit sangat rasanya"
- P002 -



"I really can't tolerate air conditioning, if it's too strong, my asthma attacks come on immediately. That's why I sometimes have to take leave and stay home until I get better."

"Aircond memang tak boleh kena, kalau kuat sangat terus asthma datang. Ganggu kerja. Sebab tu kadang-kadang kena cuti, duduk rumah sampai baik."

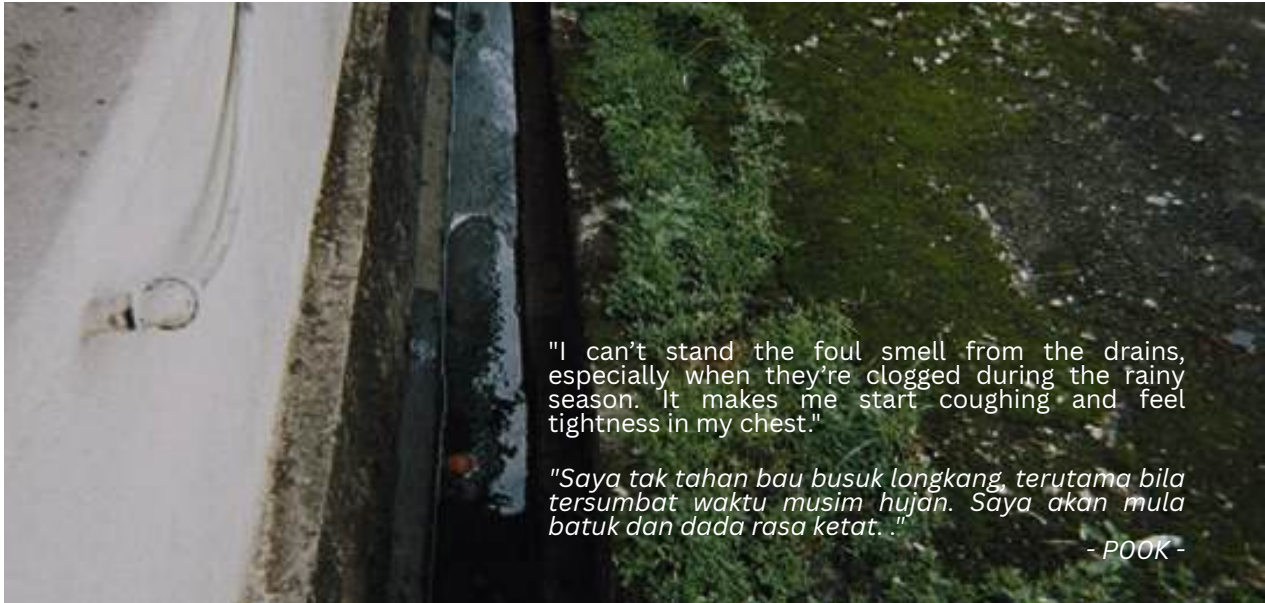
- P004 -



"At the car wash, you really can't avoid the dust because it's everywhere. When they vacuum the car, dust comes out, and I immediately have an asthma attack. After that, I quickly take Symbicort. But what can we do? Dust is invisible, yet it still disrupts our lives."

"Kat tempat cuci kereta, habuk ni memang tak boleh nak halang, sebab dia ada di mana-mana. Masa dia vacuum kereta, habuk keluar, saya terus kena serangan susah nafas. Lepas tu cepat-cepat ambik Symbicort. Tapi apa nak buat, habuk ni kita tak nampak, tapi dia tetap ganggu kehidupan kita."

- P003 -



"I can't stand the foul smell from the drains, especially when they're clogged during the rainy season. It makes me start coughing and feel tightness in my chest."

"Saya tak tahan bau busuk longkang, terutama bila tersumbat waktu musim hujan. Saya akan mula batuk dan dada rasa ketat."

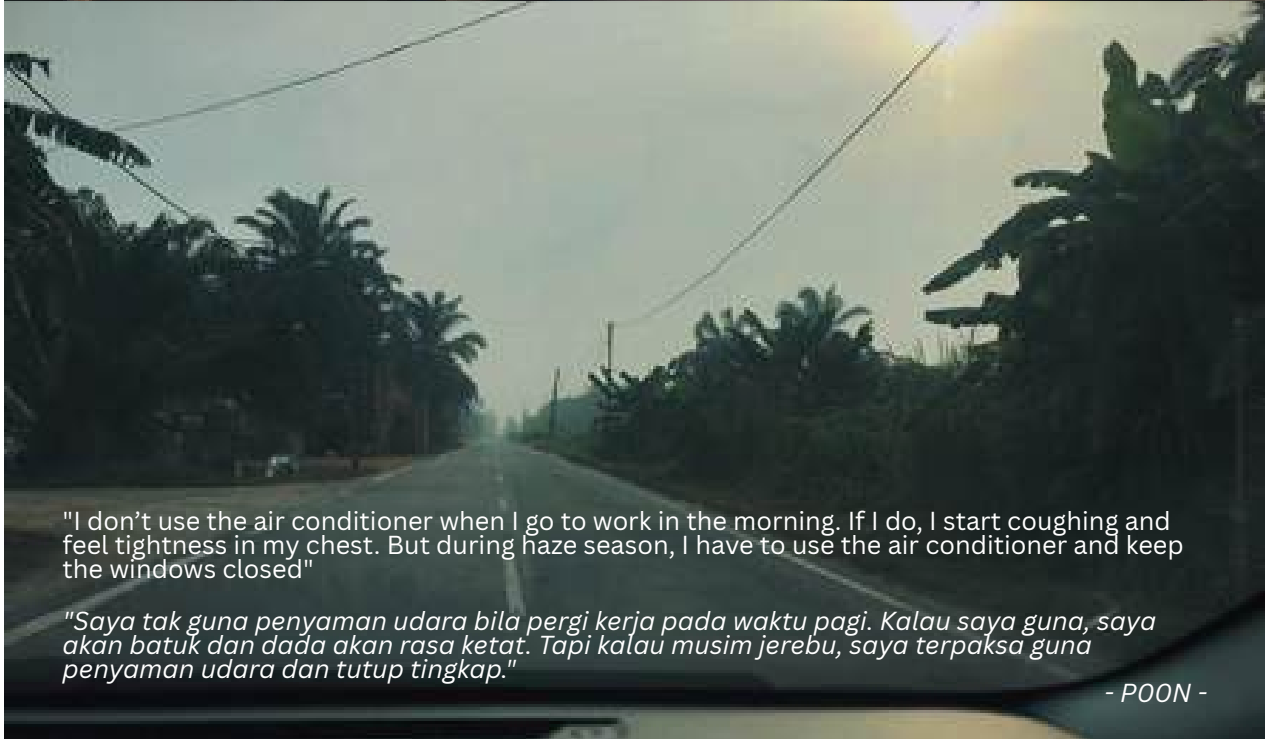
- POOK -



"Sometimes, smoke from open burning triggers my asthma. Even the haze, I can feel it before it becomes visible."

"Kadang-kadang asap dari pembakaran terbuka akan mencetuskan asma saya. Bahkan jerebu pun, saya sudah boleh rasa sebelum ia kelihatan."

- POOK -




"I don't use the air conditioner when I go to work in the morning. If I do, I start coughing and feel tightness in my chest. But during haze season, I have to use the air conditioner and keep the windows closed"

"Saya tak guna penyaman udara bila pergi kerja pada waktu pagi. Kalau saya guna, saya akan batuk dan dada akan rasa ketat. Tapi kalau musim jerebu, saya terpaksa guna penyaman udara dan tutup tingkap."

- POON -

DIETARY TRIGGERS AND FOOD-RELATED CHALLENGES

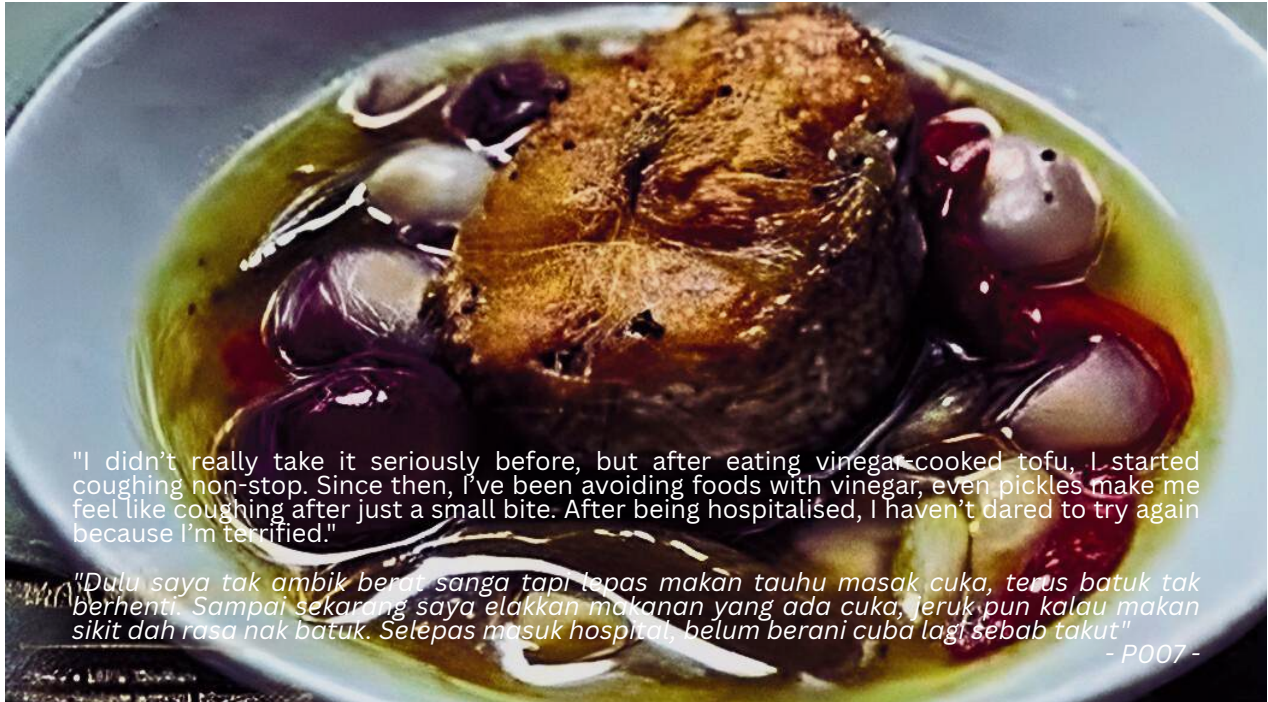
PENCETUS PEMAKANAN DAN CABARAN BERKAITAN MAKANAN



"I really want to eat this batang buruk, but I can't... just two bites and I start choking, then comes the breathlessness. I know I shouldn't eat it, but every time I see someone else enjoying it, it looks so delicious, I want it, but I just can't."

"Batang buruk ni memang saya nak makan sangat, tapi tak boleh... baru ambik dua rasa, confirm tersedak, lepas tu sempit. Dah tau tak boleh makan, tapi tiap kali tengok orang makan, sedap je nampak, nak tapi tak boleh"

- P005 -



"I didn't really take it seriously before, but after eating vinegar-cooked tofu, I started coughing non-stop. Since then, I've been avoiding foods with vinegar, even pickles make me feel like coughing after just a small bite. After being hospitalised, I haven't dared to try again because I'm terrified."

"Dulu saya tak ambik berat sanga tapi lepas makan tauhu masak cuka, terus batuk tak berhenti. Sampai sekarang saya elakkan makanan yang ada cuka, jeruk pun kalau makan sikit dah rasa nak batuk. Selepas masuk hospital, belum berani cuba lagi sebab takut"

- P007 -



"I used to love nuts like almonds, cashews, and peanuts, but every time I ate them, I would start coughing. I still tried because they're my favourites I became more cautious. Now, with consistent use of the inhaler, I can eat a little without coughing, but I'm still afraid it might get worse again."

"Dulu saya suka kacang seperti badam, gajus, kacang tanah tapi setiap kali makan, mesti batuk. Saya cuba juga sebab favorite, tapi saya lebih berjaga-jaga. Sekarang dengan inhaler yang consistent, saya boleh makan sikit-sikit tanpa batuk, tapi tetap takut kalau jadi teruk lagi."

- P007 -

"If I drink cold water, it can trigger my asthma. It starts with a cough, then the wheezing begins. Sometimes people say, 'If you drink just a little, it won't kill you.' But we're the ones who suffer, they'll never understand."

"Kalau saya minum air sejuk, asma saya boleh datang. Mula-mula batuk, lepas tu mula la semput. Kadang-kadang orang cakap, 'kalau minum sikit je, tak mati pun.' Kita yang menanggung, mereka takkan faham."

- POOH -




"Nasi lemak, oily, and very delicious, but even if I eat just a little, the symptoms start right away. So, I'm very careful with food, but people say I'm fussy and difficult. They don't understand what it feels like to struggle to breathe."

"Nasi lemak, nasi berminyak dan sangat sedap, tapi kalau saya makan walaupun sikit, terus mula ada simptom. Jadi, saya memang sangat berhati-hati dengan makanan, tapi orang kata saya cerewet dan menyusahkan. Mereka tak faham macam mana rasanya bila sesak nafas."

- POOH -

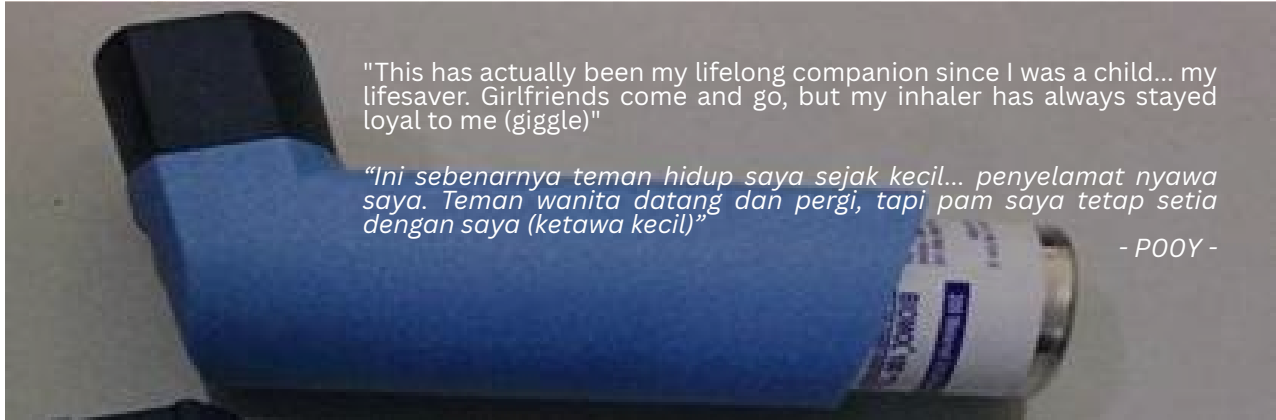
MANAGING ILLNESS AND MEDICAL ADHERENCE

**PENGURUSAN PENYAKIT DAN KEPATUHAN DALAM
RAWATAN**



“The doctor gave me this inhaler. I tried using it many times, but it didn’t work well, only then did the doctor ask me to use this spacer. When I use it, I feel some relief, especially in my chest.”

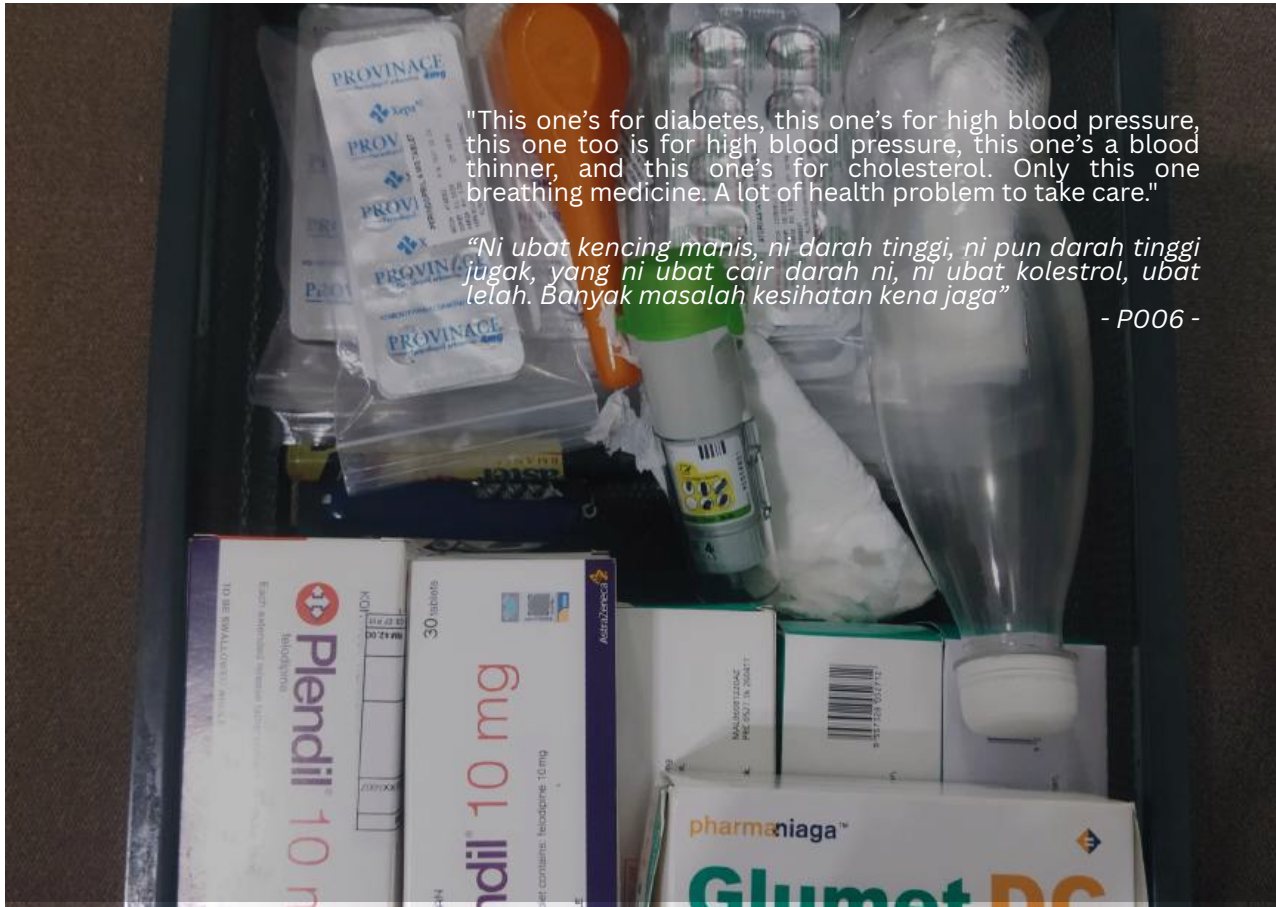
“Doktor bagi saya inhaler ni. Dah banyak kali cuba, tapi tak berjaya, baru dia suruh pakai corong ni. Kalau pakai ni, lega sikit, terasa di dada.”
- P002 -



"This has actually been my lifelong companion since I was a child... my lifesaver. Girlfriends come and go, but my inhaler has always stayed loyal to me (giggle)"

"Ini sebenarnya teman hidup saya sejak kecil... penyelamat nyawa saya. Teman wanita datang dan pergi, tapi pam saya tetap setia dengan saya (ketawa kecil)"

- P00Y -



"This one's for diabetes, this one's for high blood pressure, this one too is for high blood pressure, this one's a blood thinner, and this one's for cholesterol. Only this one breathing medicine. A lot of health problem to take care."

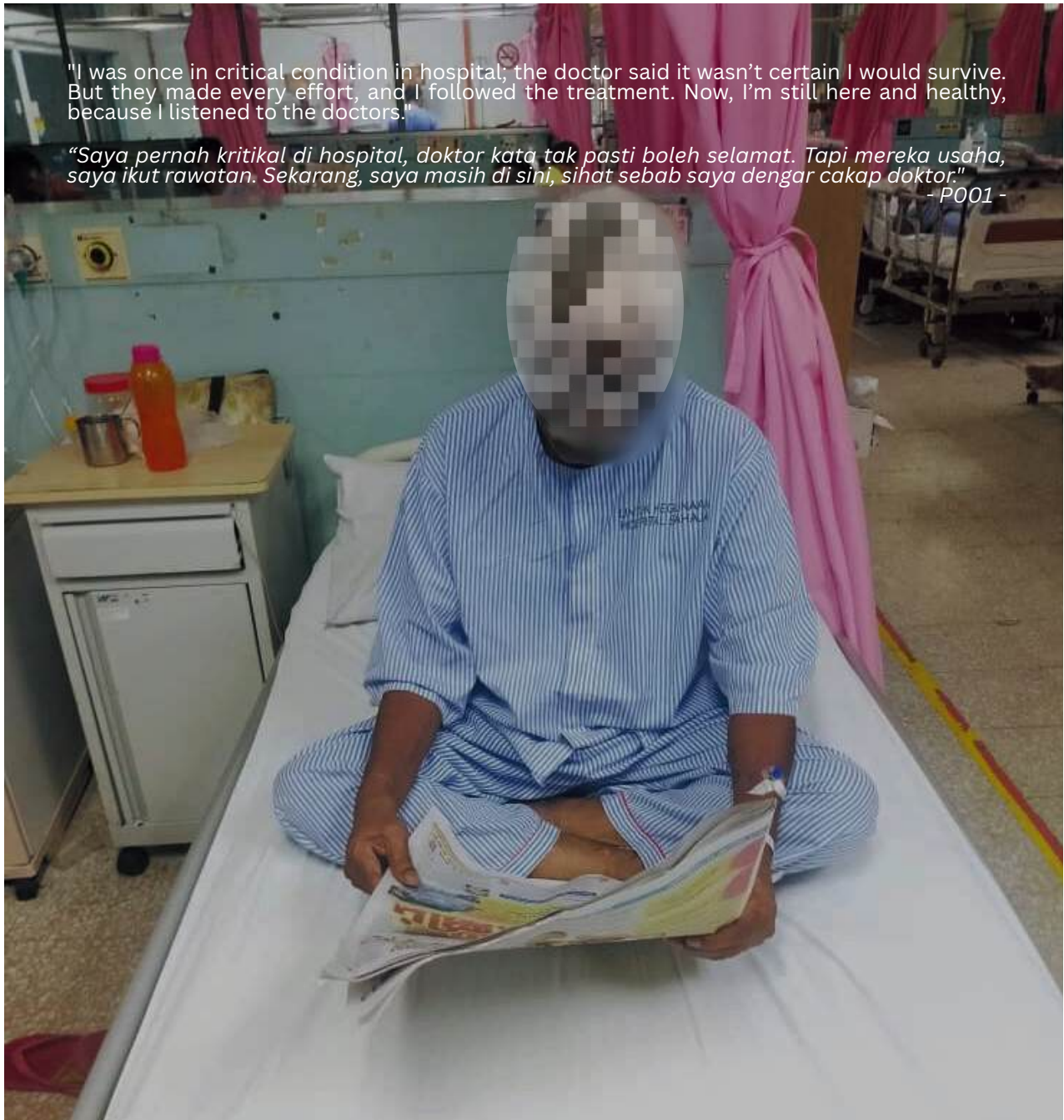
"Ni obat kencing manis, ni darah tinggi, ni pun darah tinggi jugak, yang ni obat cair darah ni, ni obat kolestrol, ubat lelah. Banyak masalah kesihatan kena jaga"

- P006 -

"I was once in critical condition in hospital; the doctor said it wasn't certain I would survive. But they made every effort, and I followed the treatment. Now, I'm still here and healthy, because I listened to the doctors."

"Saya pernah kritikal di hospital, doktor kata tak pasti boleh selamat. Tapi mereka usaha, saya ikut rawatan. Sekarang, saya masih di sini, sihat sebab saya dengar cakap doktor."

- P001 -





"I've been using this since I was admitted to hospital, they told me to buy it. It's been 5-6 years now. I only inhale the ball halfway up; if it goes too high, it gets difficult. I use it once a day and I feel a bit better after using it."

"Saya pakai ini sejak masuk hospital dulu, mereka suruh beli. Dah 5-6 tahun pakai. Saya sedut bola tu sampai tengah saja, kalau naik tinggi sangat, nanti susah. Pakai satu hari sekali, dan rasa okey sikit lepas buat."

- P013 -



"Every night, I must wear oxygen. Without it, it's hard to breathe and I can't sleep. I used to try going without it, but I felt tightness in my chest and couldn't get enough air. Before I started using the oxygen machine, my oxygen level was only around 91-92%, but when I use it, it goes up to 95-96%. The doctor said I need to use it for at least 16 hours a day. During the day, I also use it when I feel my body is too tired. When I wear the oxygen, I feel relieved, I can continue with activities, watch TV, or rest more comfortably. Without it, it feels like I can't breathe."

"Setiap malam, saya wajib pakai oxygen. Kalau tak, nafas susah, tak boleh tidur. Dulu, saya cuba tak pakai, tapi rasa dada sesak, nafas pun tak cukup. Mesin oksigen yang saya pakai, dulu bacaan hanya 91-92%, tapi bila pasang oxygen, bacaan jadi 95-96. Doktor kata saya perlu pakai sekurang-kurangnya 16 jam sehari. Kalau siang, saya pakai juga bila terasa perlu, bila tubuh tak larat. Bila pakai oxygen, saya rasa lega, boleh teruskan aktiviti, tengok TV, atau rehat dengan lebih selasa. Kalau tak pakai, rasa macam tak boleh bernafas."

WORK, PRODUCTIVITY AND ADAPTATION

PEKERJAAN, PRODUKTIVITI DAN PENYESUAIAN DIRI



"This lorry is my livelihood now. Inside this big lorry are dreams and challenges. Every day, I wake up early and return home late. But there's still hope, to finish building the house, to retire at my hometown with my family, and to find lighter work. Sometimes I get short of breath when I have to climb up into the lorry. Hopefully, God will grant me health and sustenance to keep going in life."

"Lori inilah kerja saya sekarang. Dalam lori besar ni ada impian, ada cabaran. Setiap hari bangun awal, balik lambat. Tapi harapan tetap ada – siapkan rumah, rehat di kampung halaman bersama keluarga, dan cari kerja yang lebih ringan. Kadang-kadang dapat susah nafas semasa kene panjat naik atas lori. Mudah-mudahan Allah beri kesihatan dan rezeki untuk teruskan hidup."



"I used to be active doing henna, even before I got married. But now I've slowed down. Ever since I forgot to bring my medicine during an attack in 2022, I've been afraid to take jobs far from home. Even if there's a cat nearby, I start sneezing. Luckily, I now keep an inhaler in the car. For now, I'm taking a break, I'm afraid of having another attack while doing henna."

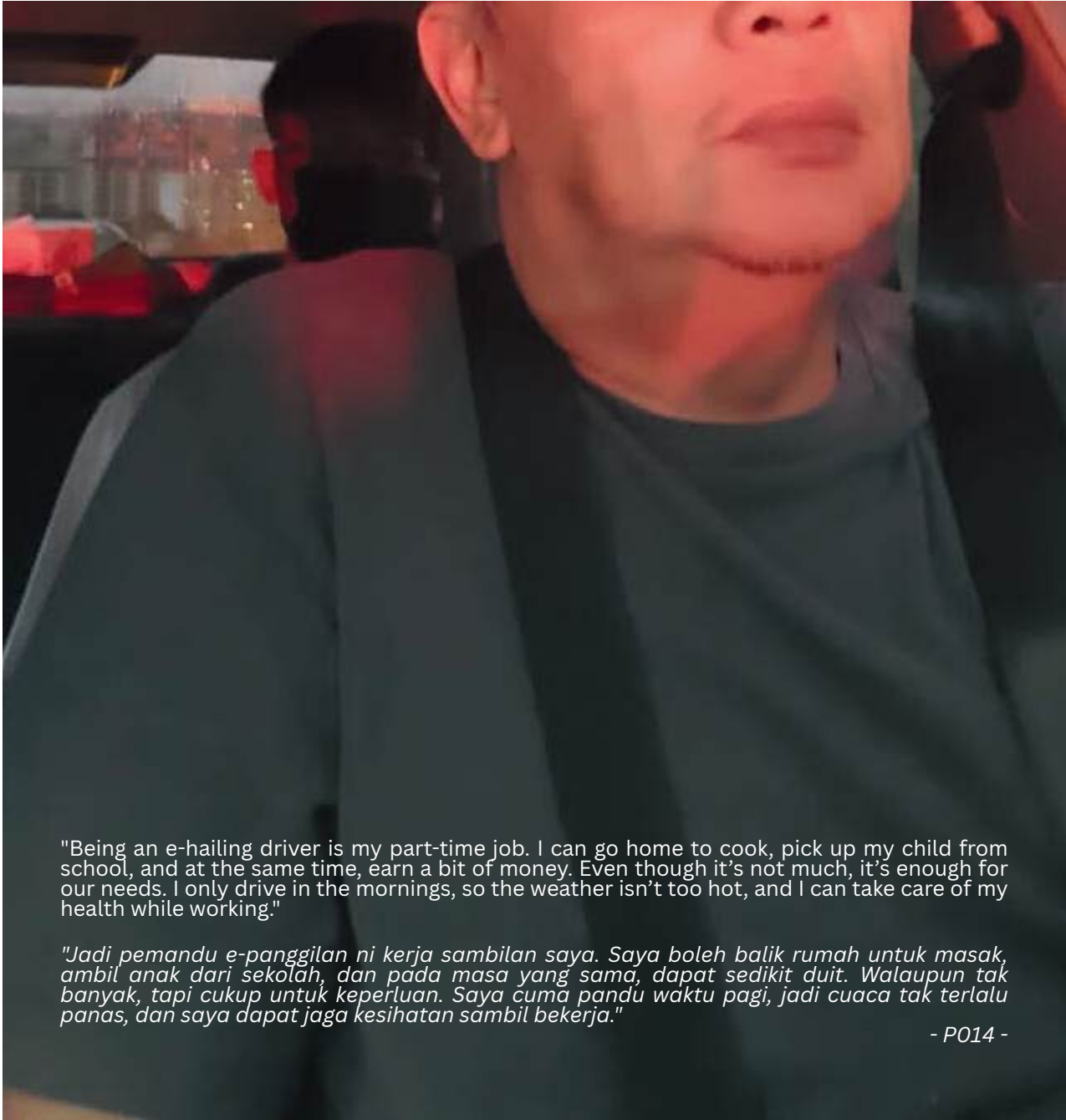
"Dulu saya aktif buat inai, dari zaman bujang lagi. Tapi sekarang saya dah slow. Sejak lupa bawak ubat masa kena serangan 2022 tu, saya takut nak ambik job jauh-jauh. Kalau ada kucing pun habis, saya dah bersin. Nasib baik sekarang saya dah letak satu pam dalam kereta. Rehat dulu lah, takut tengah buat inai kena lagi"

- P005 -



"There's a lot of dust at my workplace, so I have to wear a mask to cover my nose. If I don't, it can really make my asthma worse. The dust and polluted air at work are definitely among the reasons I developed asthma. If I'm not careful, I start having trouble breathing and can't stop coughing. So wearing a mask is important, and I have to be mindful of my surroundings."


"Tempat kerja saya banyak habuk, jadi saya kena pakai mask untuk tutup hidung. Kalau tak, memang boleh buat asma saya makin teruk. Habuk dan udara kotor di tempat kerja ni memang salah satu punca saya kena asma. Kalau tak berjaga, mesti susah nak bernafas dan batuk tak berhenti. Jadi, pakai mask tu penting, dan kena hati-hati dengan keadaan sekeliling."



"Being an e-hailing driver is my part-time job. I can go home to cook, pick up my child from school, and at the same time, earn a bit of money. Even though it's not much, it's enough for our needs. I only drive in the mornings, so the weather isn't too hot, and I can take care of my health while working."

"Jadi pemandu e-panggilan ni kerja sambilan saya. Saya boleh balik rumah untuk masak, ambil anak dari sekolah, dan pada masa yang sama, dapat sedikit duit. Walaupun tak banyak, tapi cukup untuk keperluan. Saya cuma pandu waktu pagi, jadi cuaca tak terlalu panas, dan saya dapat jaga kesihatan sambil bekerja."

- P014 -



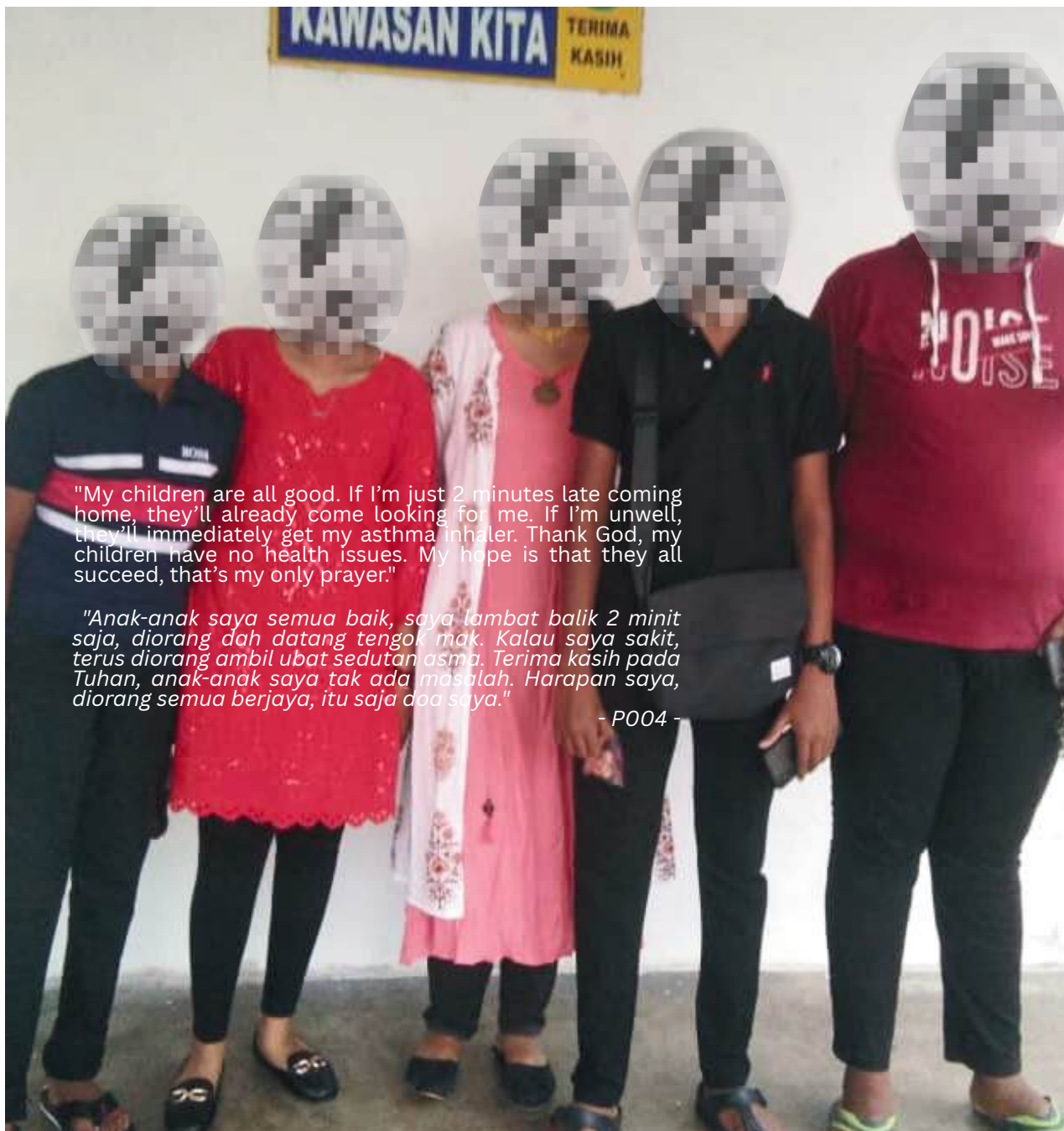
"I admire her resilience. She's a woman who lives near my house, 60 years old and living with asthma. She runs a food stall and starts cooking every day at 3 p.m., opening the stall with her husband at 6 p.m. She works hard, even though she occasionally needs to use an inhaler. But she never uses asthma as an excuse, not once, to earn a living and keep going in life.

"Saya kagum dengan ketabahan dia. Ini seorang wanita yang tinggal berhampiran rumah saya. Umurnya 60 tahun dan dia ada asma. Dia ada gerai makan dan mula memasak setiap hari pada pukul 3 petang. Dia buka gerainya pada pukul 6 petang bersama suaminya. Dia bekerja keras walaupun sekali-sekala perlu gunakan inhaler. Tapi dia tak pernah anggap asma sebagai alasan untuk mencari rezeki dan teruskan hidup, tidak, tak pernah."

- POOK -

SOCIAL SUPPORT AND FAMILY

SOKONGAN SOSIAL DAN KELUARGA



"My children are all good. If I'm just 2 minutes late coming home, they'll already come looking for me. If I'm unwell, they'll immediately get my asthma inhaler. Thank God, my children have no health issues. My hope is that they all succeed, that's my only prayer."

"Anak-anak saya semua baik, saya lambat balik 2 minit saja, diorang dah datang tengok mak. Kalau saya sakit, terus diorang ambil ubat sedutan asma. Terima kasih pada Tuhan, anak-anak saya tak ada masalah. Harapan saya, diorang semua berjaya, itu saja doa saya."

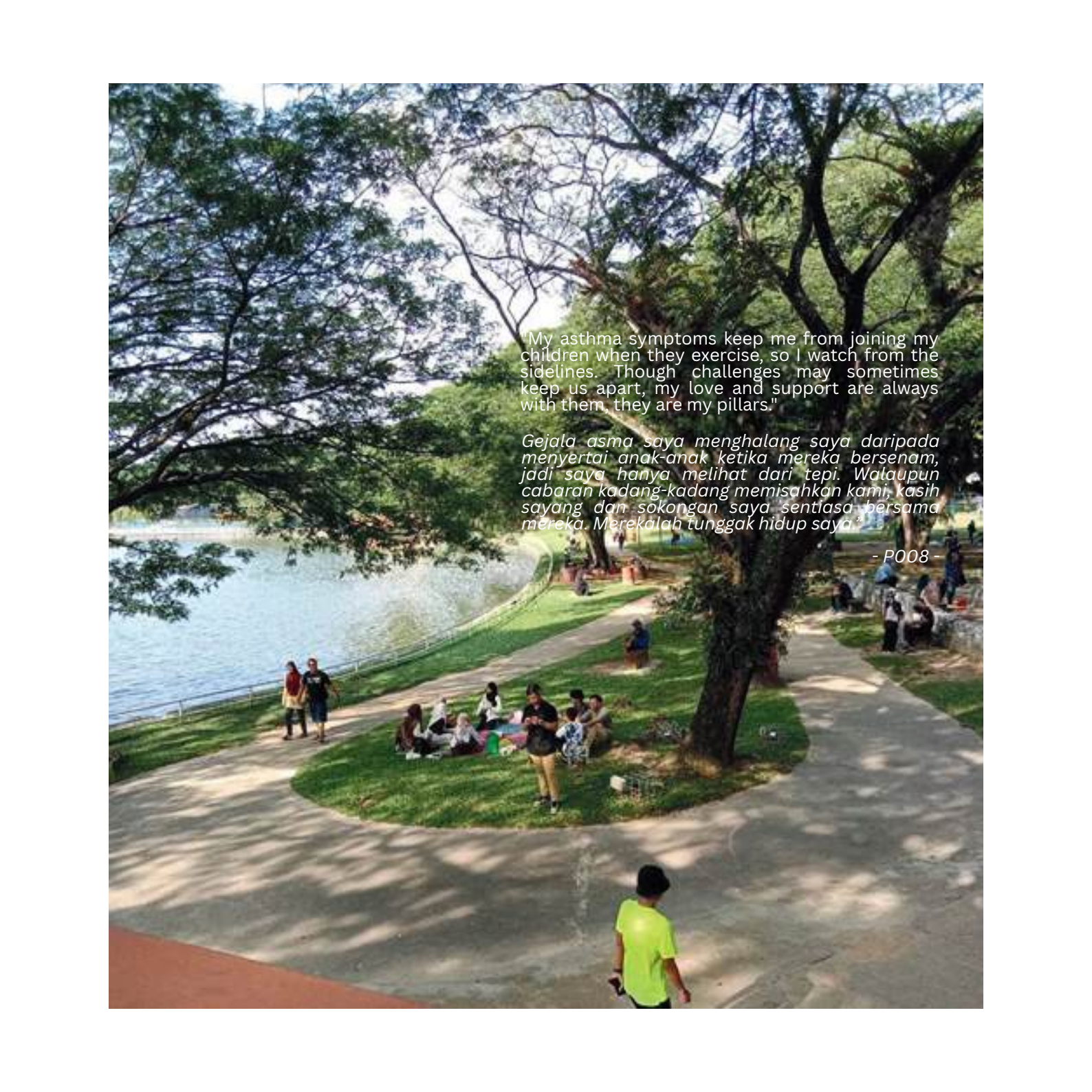
- P004 -



"In the morning, I go sit at the shop, hang out with friends, and chat. I feel relieved when I get to talk with them. Sometimes, when I'm with friends, I can forget about the pain for a while. Without friends, I feel lonely. My friends know about my illness, and they always remind me not to go out alone. They help me when I'm short on money, treating me to food and drinks. Since all my children are grown up, it's just my friends who are around here. I feel stressed, but the support from friends and family really helps. Without them, I don't know how I would carry on."

"Pagi saya pergi duduk kedai, lepak dengan kawan-kawan, borak-borak. Rasa lega bila dapat borak dengan diorang. Kadang-kadang bila bersama kawan, saya boleh lupakan sakit sekejap. Kalau tak ada kawan, saya rasa sunyi. Kawan-kawan tahu tentang sakit saya, mereka selalu ingatkan jangan keluar seorang. Mereka bantu saya kalau saya kekurangan duit, belanja makan, minum. Sebab anak-anak semua dah besar, kawan-kawan je yang ada dekat sini. Saya stress, tapi sokongan kawan dan keluarga banyak membantu. Kalau tak ada mereka, saya tak tahu macam mana nak teruskan."

- P012 -



"My asthma symptoms keep me from joining my children when they exercise, so I watch from the sidelines. Though challenges may sometimes keep us apart, my love and support are always with them, they are my pillars."

Gejala asma saya menghalang saya daripada menyertai anak-anak ketika mereka bersenam, jadi saya hanya melihat dari tepi. Walaupun cabaran kadang-kadang memisahkan kami, kasih sayang dan sokongan saya sentiasa bersama mereka. Merekalah tunggak hidup saya."

- P008 -



"Lily has been with us for 13 years. I only got asthma 5 years ago. I want to show that it has nothing to do with asthma, not for everyone. Pets aren't necessarily linked to asthma. She sniffs, cuddles, and I love it. Even though the doctor said to avoid pets. My kids are all grown up. They don't hug us anymore, no more cuddles. I want that when I come home, there's someone to hug me. (laughs) That's why I still take care of Lily."

"Lily sudah bersama kami selama 13 tahun. Saya kena asma baru 5 tahun lepas. Saya nak tunjuk yang ia tak ada kena-mengena dengan asma, bukan semua orang. Haiwan peliharaan tak semestinya ada kaitan dengan asma. Dia cium, peluk, saya suka. Walaupun doktor cakap elakkan haiwan peliharaan. Anak-anak saya semua dah besar. Mereka dah tak nak peluk saya, tak ada pelukan. Saya nak seseorang, bila saya balik rumah, ada yang peluk saya. (ketawa) Sebab itu saya masih jaga Lily."

- POON -



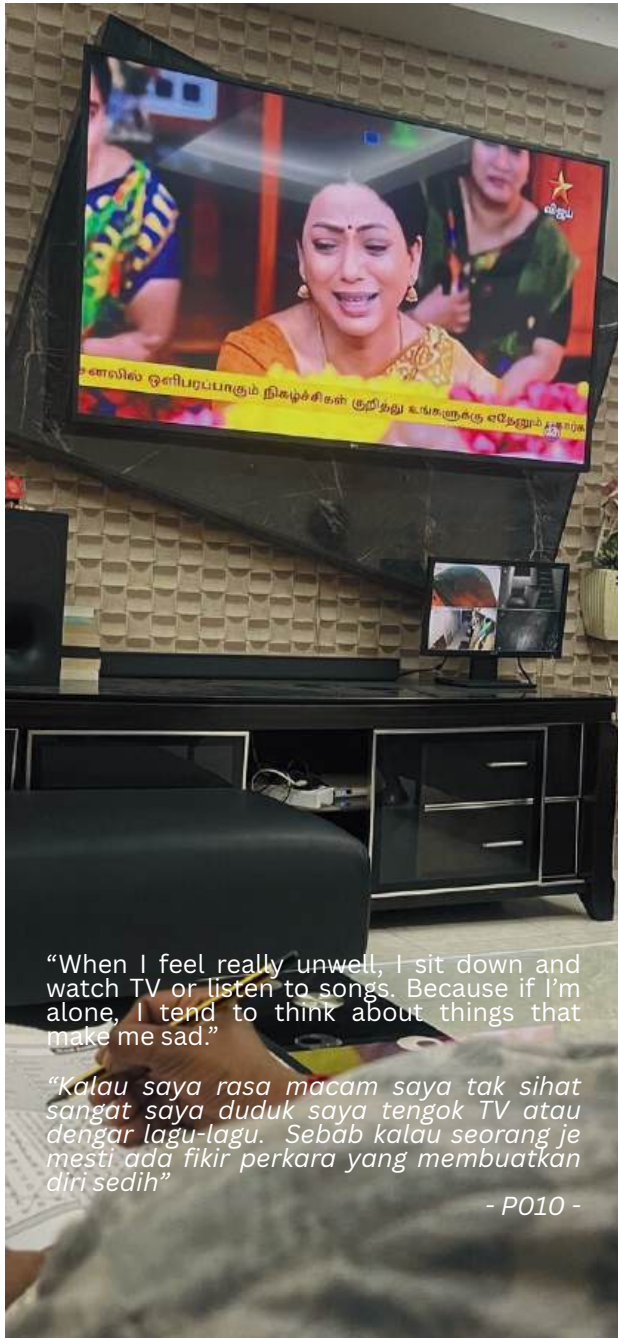
"I really love children. When I'm with them, I don't think about my problems. Whether I'm sick or stressed, I can forget all that. We smile with our lips, but children's smiles come from the heart, their hearts are pure. These smiles can heal."

"Saya sangat suka kanak-kanak. Bila bersama mereka, saya tak fikirkan masalah saya. Sama ada saya sakit atau stres, semua itu saya boleh lupakan. Kita senyum dari bibir, tapi senyuman kanak-kanak datang dari hati, hati mereka suci. Senyuman ini boleh menyembuhkan."

-POOJ-

COPING MECHANISMS AND MENTAL HEALTH

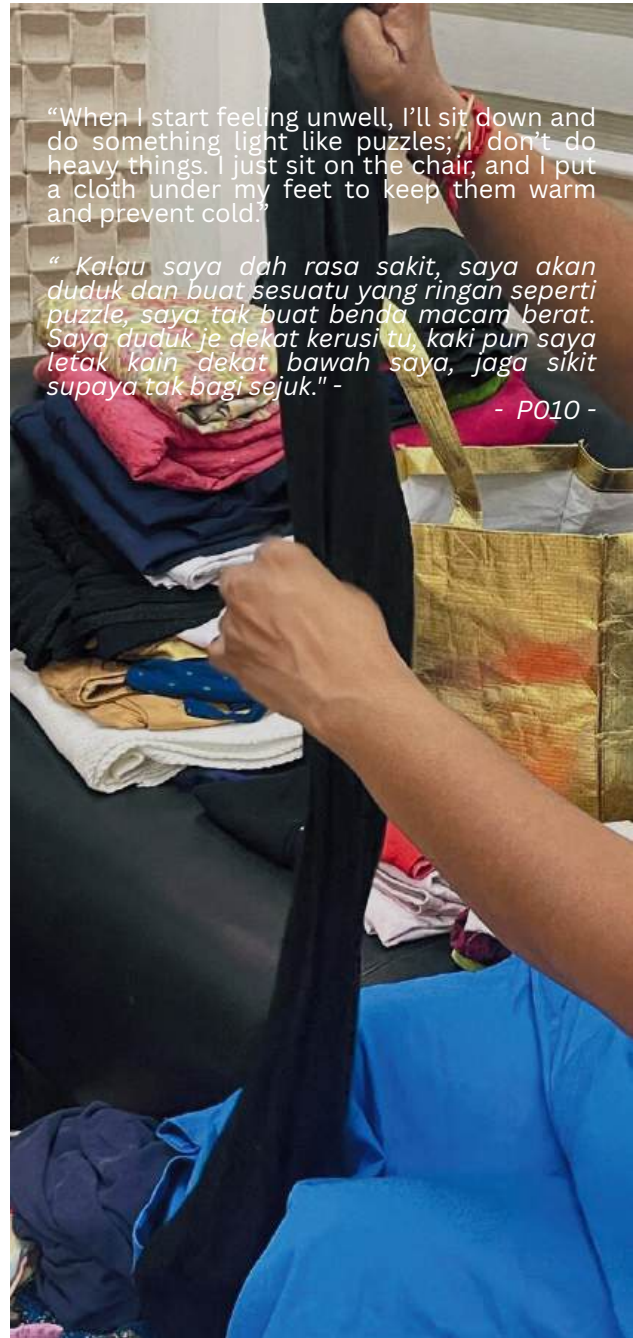
MEKANISME MENGATASI DAN KESIHATAN MENTAL



“When I feel really unwell, I sit down and watch TV or listen to songs. Because if I’m alone, I tend to think about things that make me sad.”

“Kalau saya rasa macam saya tak sihat sangat saya duduk saya tengok TV atau dengar lagu-lagu. Sebab kalau seorang je mesti ada fikir perkara yang membuatkan diri sedih”

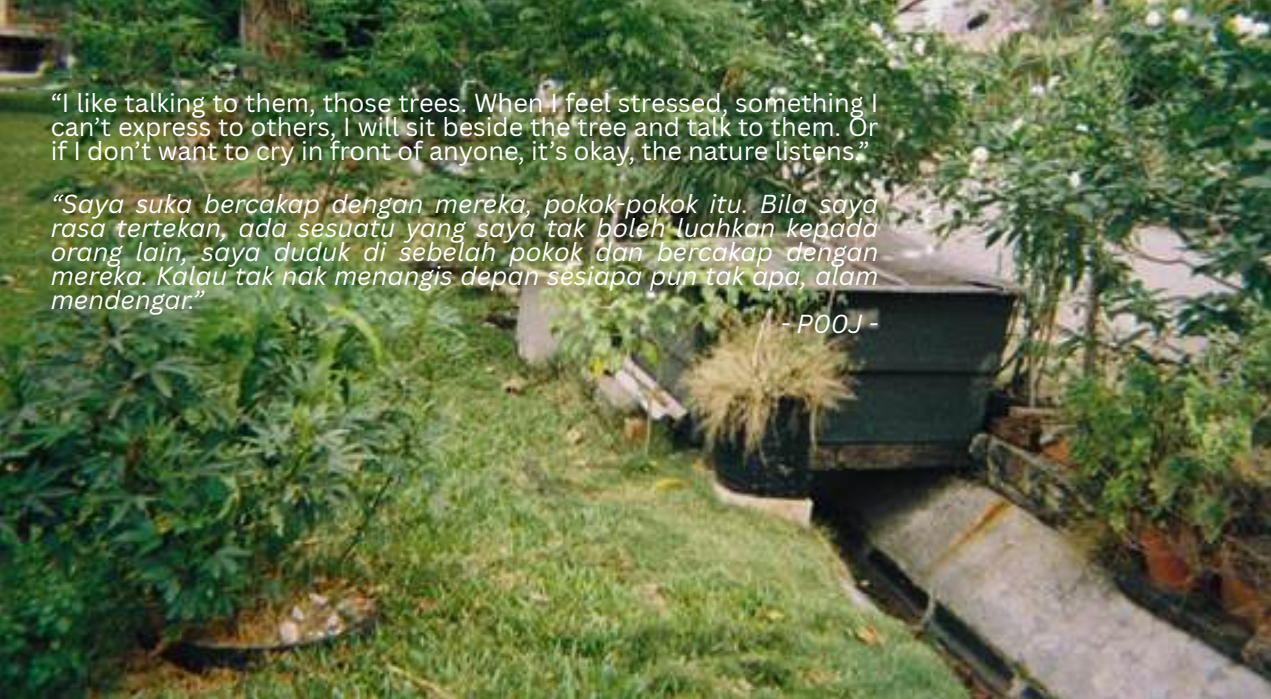
- P010 -



“When I start feeling unwell, I’ll sit down and do something light like puzzles; I don’t do heavy things. I just sit on the chair, and I put a cloth under my feet to keep them warm and prevent cold.”

“ Kalau saya dah rasa sakit, saya akan duduk dan buat sesuatu yang ringan seperti puzzle, saya tak buat benda macam berat. Saya duduk je dekat kerusi tu, kaki pun saya letak kain dekat bawah saya, jaga sikit supaya tak bagi sejuk.” -

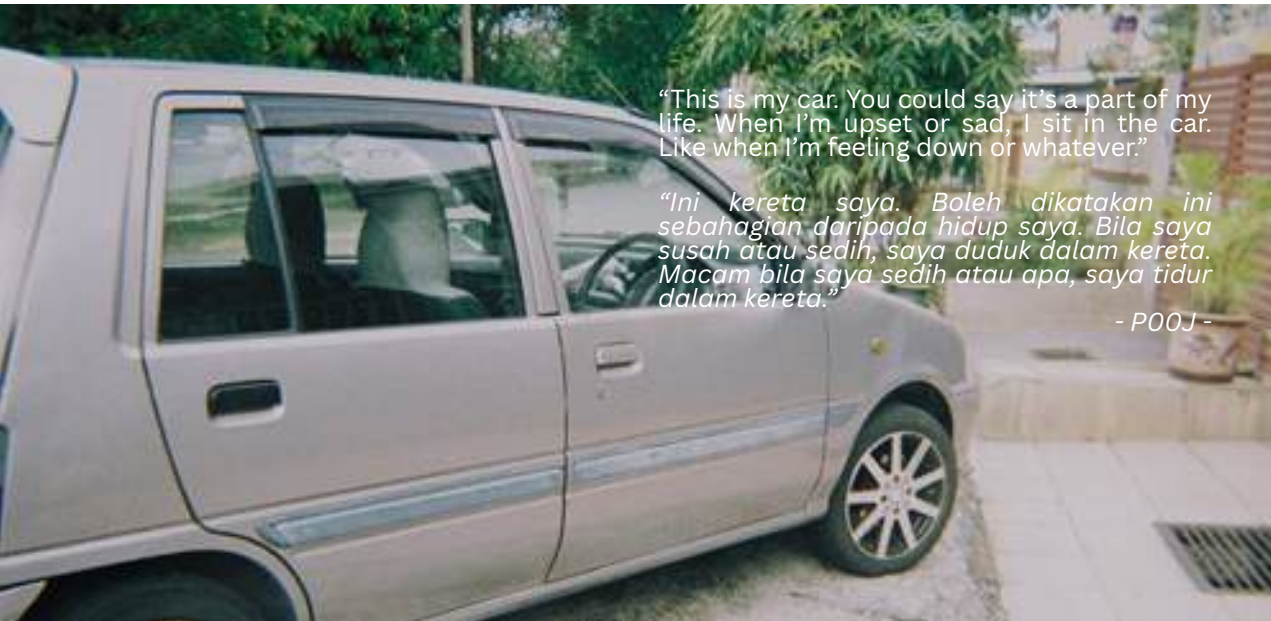
- P010 -



"I like talking to them, those trees. When I feel stressed, something I can't express to others, I will sit beside the tree and talk to them. Or if I don't want to cry in front of anyone, it's okay, the nature listens."

"Saya suka bercakap dengan mereka, pokok-pokok itu. Bila saya rasa tertekan, ada sesuatu yang saya tak boleh luahkan kepada orang lain, saya duduk di sebelah pokok dan bercakap dengan mereka. Kalau tak nak menangis depan sesiapa pun tak apa, alam mendengar."

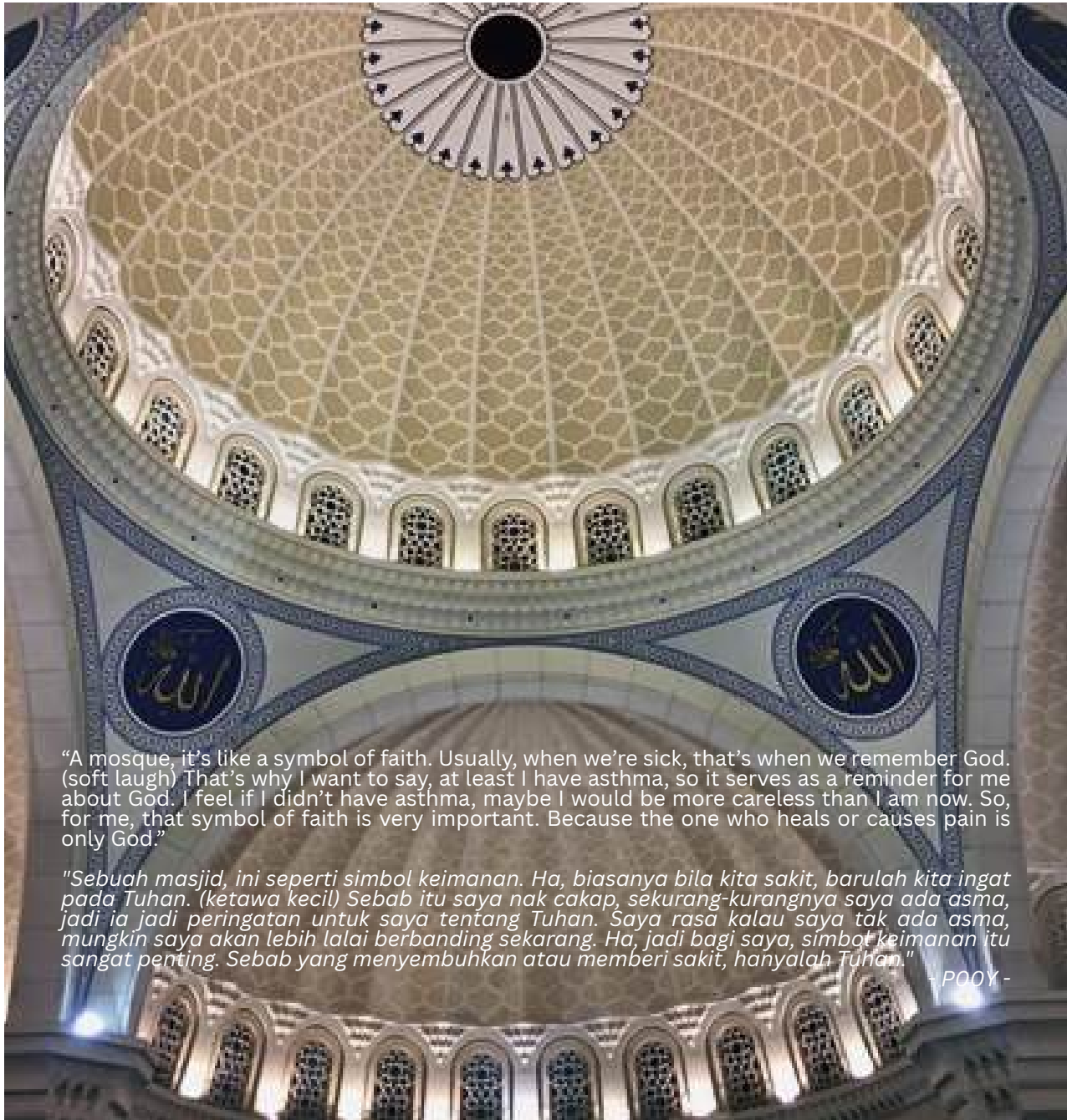
- POOJ -



"This is my car. You could say it's a part of my life. When I'm upset or sad, I sit in the car. Like when I'm feeling down or whatever."

"Ini kereta saya. Boleh dikatakan ini sebahagian daripada hidup saya. Bila saya susah atau sedih, saya duduk dalam kereta. Macam bila saya sedih atau apa, saya tidur dalam kereta."

- POOJ -



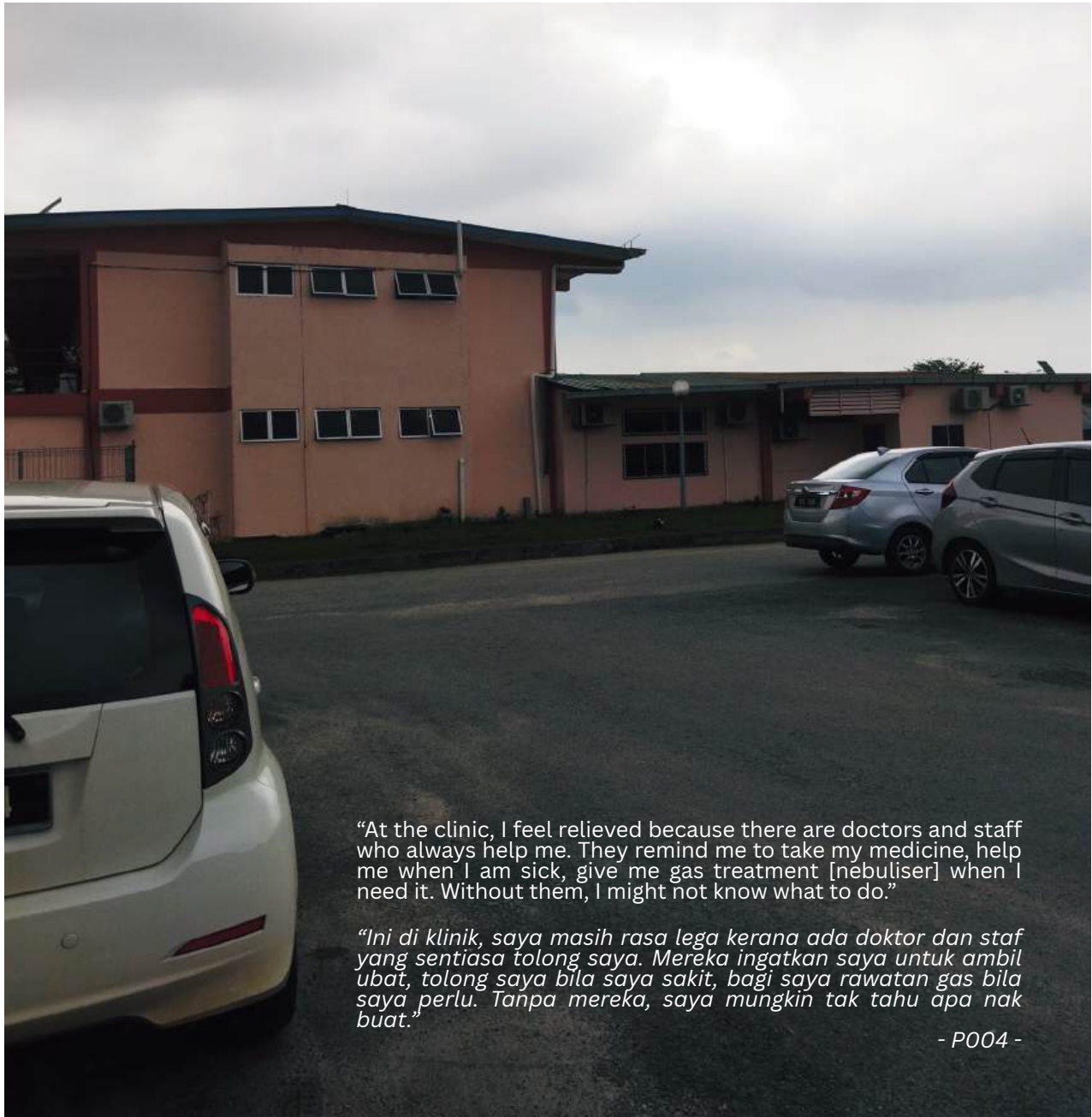
"A mosque, it's like a symbol of faith. Usually, when we're sick, that's when we remember God. (soft laugh) That's why I want to say, at least I have asthma, so it serves as a reminder for me about God. I feel if I didn't have asthma, maybe I would be more careless than I am now. So, for me, that symbol of faith is very important. Because the one who heals or causes pain is only God."

"Sebuah masjid, ini seperti simbol keimanan. Ha, biasanya bila kita sakit, barulah kita ingat pada Tuhan. (ketawa kecil) Sebab itu saya nak cakap, sekurang-kurangnya saya ada asma, jadi ia jadi peringatan untuk saya tentang Tuhan. Saya rasa kalau saya tak ada asma, mungkin saya akan lebih lalai berbanding sekarang. Ha, jadi bagi saya, simbol keimanan itu sangat penting. Sebab yang menyembuhkan atau memberi sakit, hanyalah Tuhan."

- POOY -

HEALTHCARE SYSTEM EXPERIENCES

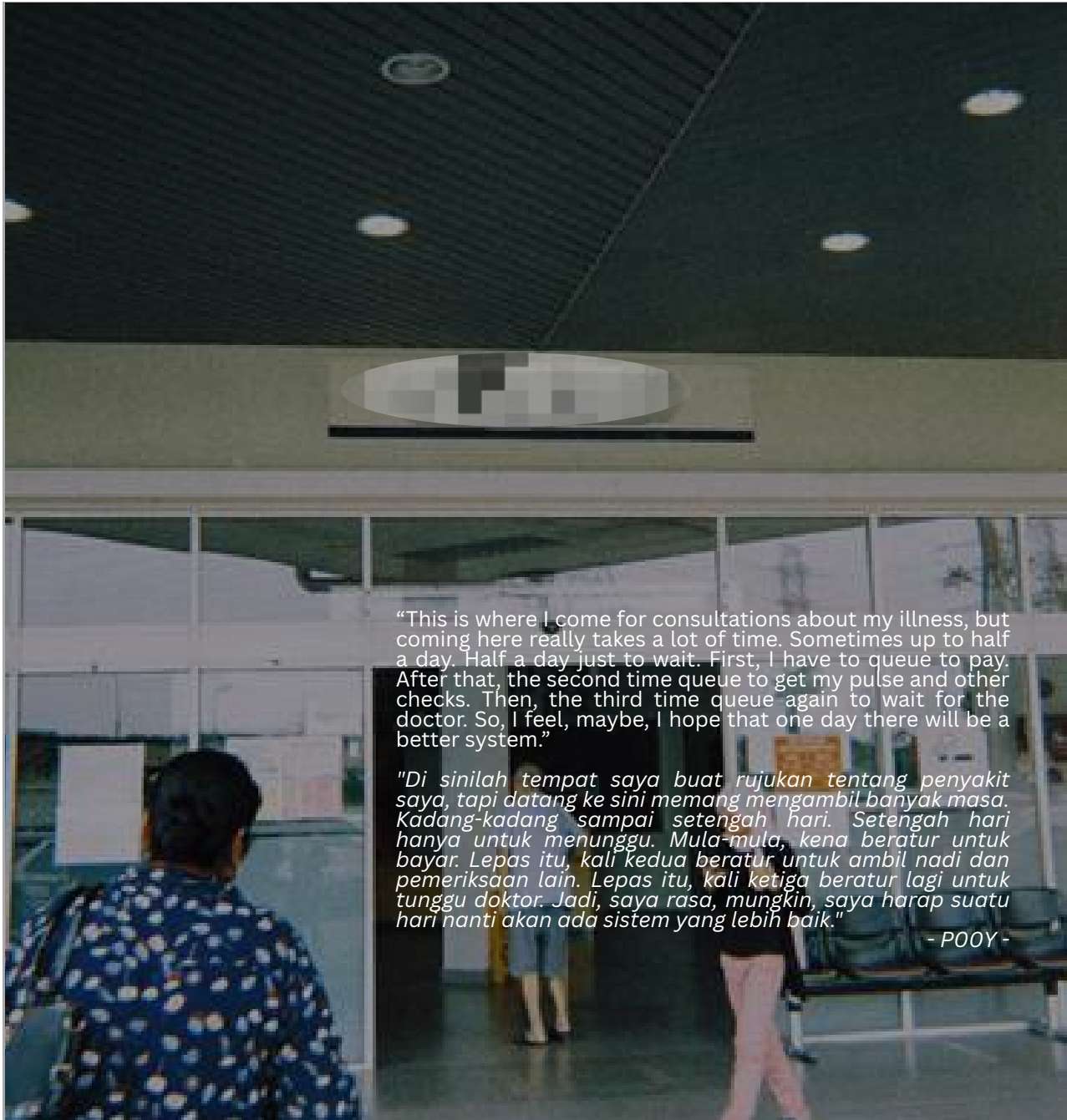
PENGALAMAN DALAM SISTEM KESIHATAN



“At the clinic, I feel relieved because there are doctors and staff who always help me. They remind me to take my medicine, help me when I am sick, give me gas treatment [nebuliser] when I need it. Without them, I might not know what to do.”

“Ini di klinik, saya masih rasa lega kerana ada doktor dan staf yang sentiasa tolong saya. Mereka ingatkan saya untuk ambil ubat, tolong saya bila saya sakit, bagi saya rawatan gas bila saya perlu. Tanpa mereka, saya mungkin tak tahu apa nak buat.”

- P004 -



"This is where I come for consultations about my illness, but coming here really takes a lot of time. Sometimes up to half a day. Half a day just to wait. First, I have to queue to pay. After that, the second time queue to get my pulse and other checks. Then, the third time queue again to wait for the doctor. So, I feel, maybe, I hope that one day there will be a better system."

"Di sinilah tempat saya buat rujukan tentang penyakit saya, tapi datang ke sini memang mengambil banyak masa. Kadang-kadang sampai setengah hari. Setengah hari hanya untuk menunggu. Mula-mula, kena beratur untuk bayar. Lepas itu, kali kedua beratur untuk ambil nadi dan pemeriksaan lain. Lepas itu, kali ketiga beratur lagi untuk tunggu doktor. Jadi, saya rasa, mungkin, saya harap suatu hari nanti akan ada sistem yang lebih baik."

- POOY -

Nama

Tarikh.....

6/5/18

Minum

Sudu Teh / Besar
ml

Kali Sehari
Sebelum / Selepas
Makan

Makan

Biji / Kapsul

Pagi / Petang / Malam
/ Bila Perlu

Kegunaan:

(petang)

Nama Ubat:

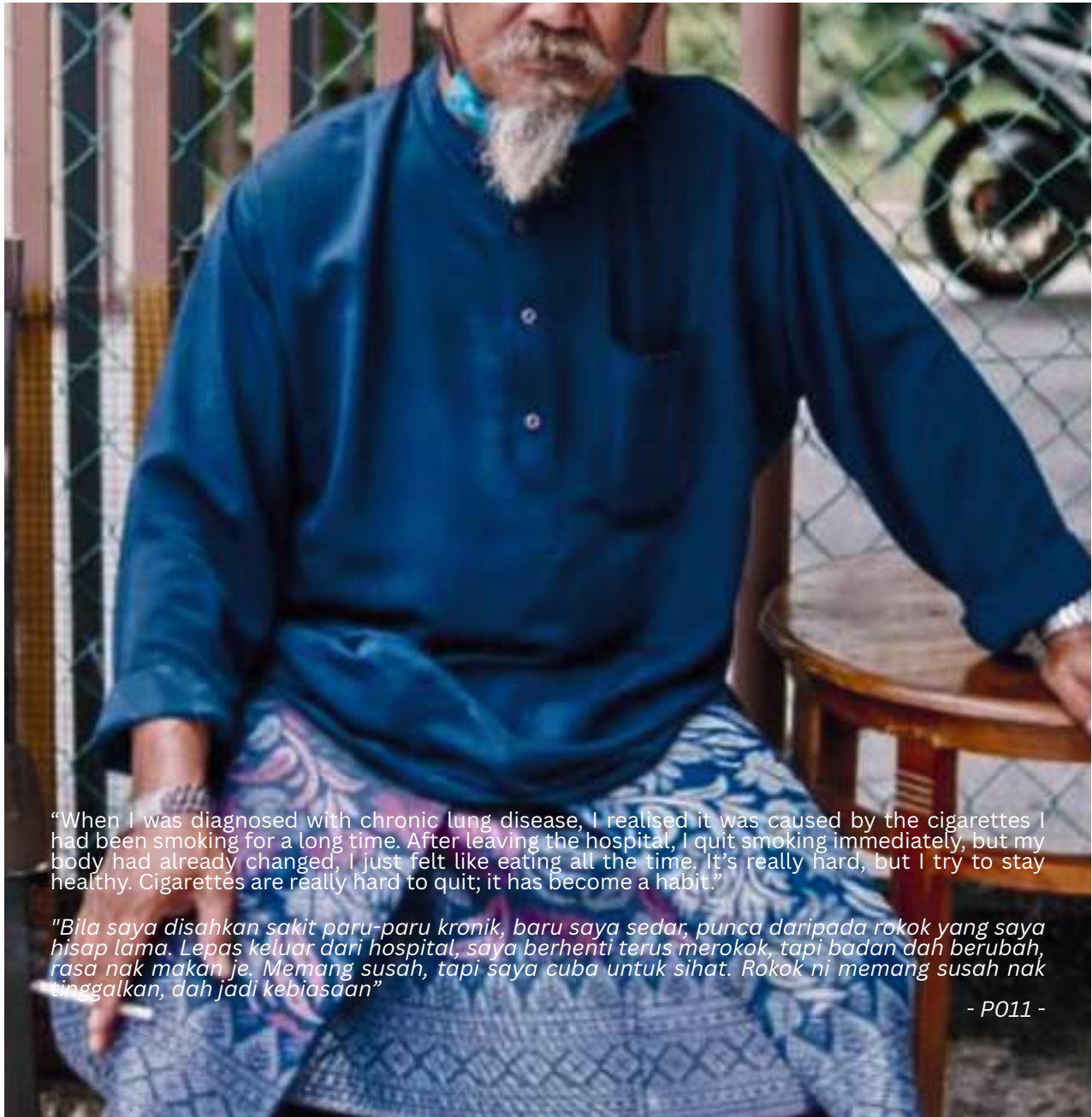
"This clinic is special. The doctor explains, like how and why I got this. Why I can't take certain things. He talks like he's chatting with a friend. He's not the type to rush, not like that. He takes time to talk with me."

"Klinik ini istimewa. Doktor terangkan, macam mana, kenapa saya kena ini. Kenapa saya tak boleh ambil benda itu. Dia bercakap macam bercerita dengan kawan. Ahh, dia bukan jenis yang nak cepat-cepat, bukan macam itu. Dia luangkan masa berbual dengan saya."

- POONI -

SMOKING AND BEHAVIOUR CHANGE

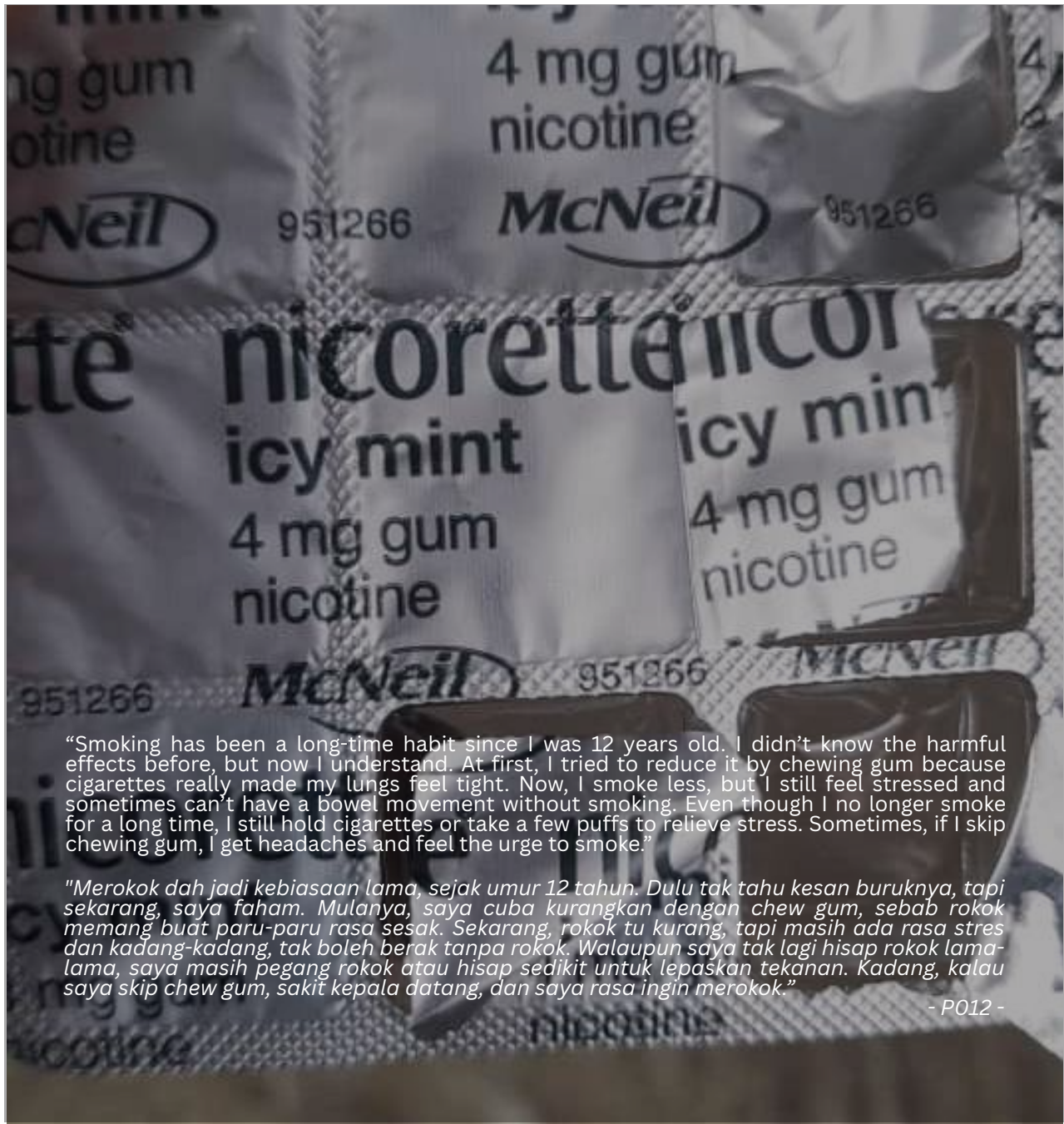
TABIAT MEROKOK DAN PERUBAHAN TINGKAH LAKU



“When I was diagnosed with chronic lung disease, I realised it was caused by the cigarettes I had been smoking for a long time. After leaving the hospital, I quit smoking immediately, but my body had already changed, I just felt like eating all the time. It’s really hard, but I try to stay healthy. Cigarettes are really hard to quit; it has become a habit.”

"Bila saya disahkan sakit paru-paru kronik, baru saya sedar, punca daripada rokok yang saya hisap lama. Lepas keluar dari hospital, saya berhenti terus merokok, tapi badan dah berubah, rasa nak makan je. Memang susah, tapi saya cuba untuk sihat. Rokok ni memang susah nak tinggalkan, dah jadi kebiasaan"

- P011 -



"Smoking has been a long-time habit since I was 12 years old. I didn't know the harmful effects before, but now I understand. At first, I tried to reduce it by chewing gum because cigarettes really made my lungs feel tight. Now, I smoke less, but I still feel stressed and sometimes can't have a bowel movement without smoking. Even though I no longer smoke for a long time, I still hold cigarettes or take a few puffs to relieve stress. Sometimes, if I skip chewing gum, I get headaches and feel the urge to smoke."

"Merokok dah jadi kebiasaan lama, sejak umur 12 tahun. Dulu tak tahu kesan buruknya, tapi sekarang, saya faham. Mulanya, saya cuba kurangkan dengan chew gum, sebab rokok memang buat paru-paru rasa sesak. Sekarang, rokok tu kurang, tapi masih ada rasa stres dan kadang-kadang, tak boleh berak tanpa rokok. Walaupun saya tak lagi hisap rokok lama-lama, saya masih pegang rokok atau hisap sedikit untuk lepaskan tekanan. Kadang, kalau saya skip chew gum, sakit kepala datang, dan saya rasa ingin merokok."

"Before, I used to hang out with friends every week, drinking beer and chatting aimlessly for hours. I admit, smoking and drinking alcohol for many years may have caused my cancer. After surgery, I stopped drinking and smoking and hope to live longer for my family. Although I miss hanging out longer, I still go home early because I get tired quickly. It's fun being with friends."

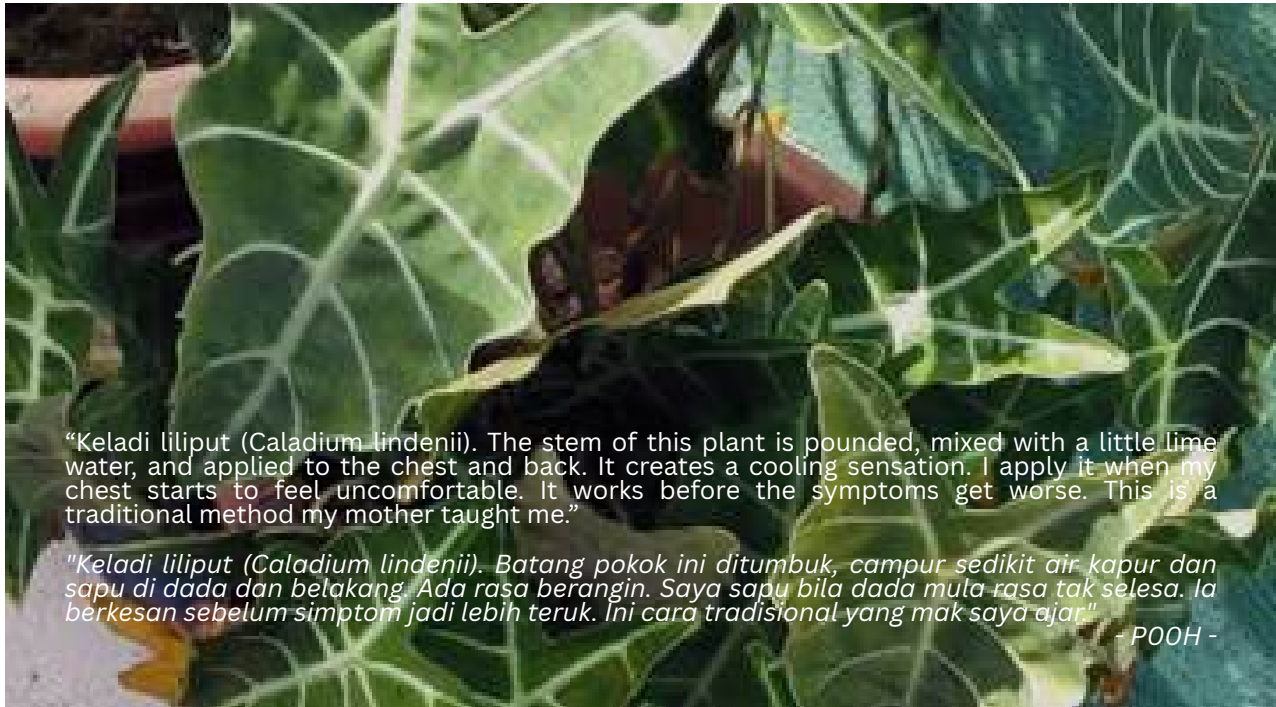
"Dulu, saya suka lepak dengan kawan-kawan setiap minggu, minum bir, borak-borak tak tentu masa. Saya akui, merokok dan minum alkohol selama bertahun-tahun mungkin jadi punca kanser saya. selepas pembedahan, saya dah berhenti minum dan merokok dan berharap saya boleh hidup lebih lama untuk keluarga. Walaupun saya rindu nak lepak lebih lama, saya tetap balik awal sebab cepat rasa penat. Seronok bersama kawan-kawan"

- P012 -



ALTERNATIVE REMEDIES AND TRADITIONAL PRACTICES

PENAWAR ALTERNATIF DAN AMALAN TRADITIONAL



"Keladi liliput (*Caladium lindenii*). The stem of this plant is pounded, mixed with a little lime water, and applied to the chest and back. It creates a cooling sensation. I apply it when my chest starts to feel uncomfortable. It works before the symptoms get worse. This is a traditional method my mother taught me."

"Keladi liliput (*Caladium lindenii*). Batang pokok ini ditumbuk, campur sedikit air kapur dan sapu di dada dan belakang. Ada rasa berangin. Saya sapu bila dada mula rasa tak selesa. Ia berkesan sebelum simptom jadi lebih teruk. Ini cara tradisional yang mak saya ajar." - POOH -



"I drink this every morning with another thing, what is it, pepper powder. This one is mixed with pepper powder. My mom's friend took this and now she no longer has asthma."

"Saya minum setiap pagi dengan satu lagi benda, apa ya, serbuk lada. Yang ini campur dengan serbuk lada. Kawan mak saya, dia ambil ini dan sekarang dia dah tak ada asma." - POONi -



"Crocodile meat, you know, they dry it until it's like paper, then they cut it into pieces, pieces like that. The crocodile meat, they cut it like that, put two pieces. They told me to boil it and drink it, saying the wheezing sound would go away. I tried it. Okay, I feel fine."

"Daging buaya kan, mereka keringkan, kering macam kertas, lepas itu mereka potong jadi kepingan, kepingan kan. Daging buaya itu, mereka potong macam itu, letak dua keping daging buaya. Dia suruh saya rebus dan minum, katanya bunyi wheezing akan hilang. Saya cuba, saya beli. Ok, saya rasa ok."

- POONI -




"I rarely use the inhaler because before using it, I drink hot water, eat salt and black pepper. After that, I can hold off the shortness of breath for about two days. That was a remedy my grandmother taught me."

"Kurang pakai inhaler sebab sebelum pakai inhaler saya minum air panas, makan garam dan lada hitam. Lepas makan bertahan daripada kene sesak nafas dalam 2 hari. Itu nenek bagi petua dulu"

- P012 -

ASPIRATIONS, HOPE, AND IDENTITY


ASPIRASI, HARAPAN DAN IDENTITI



"Twenty years of nonstop work, my only dream is to complete this house. Now it's 90% finished, but there are still things that need to be done. I hope Allah gives me health and sustenance to finish everything."

"Dua puluh tahun kerja tanpa henti, impian aku cuma satu iaitu siapkan rumah ini. Sekarang dah 90% siap, tapi masih ada yang lagi yang perlu diselesaikan. Harap Allah beri aku kesihatan dan rezeki untuk habiskan semuanya."

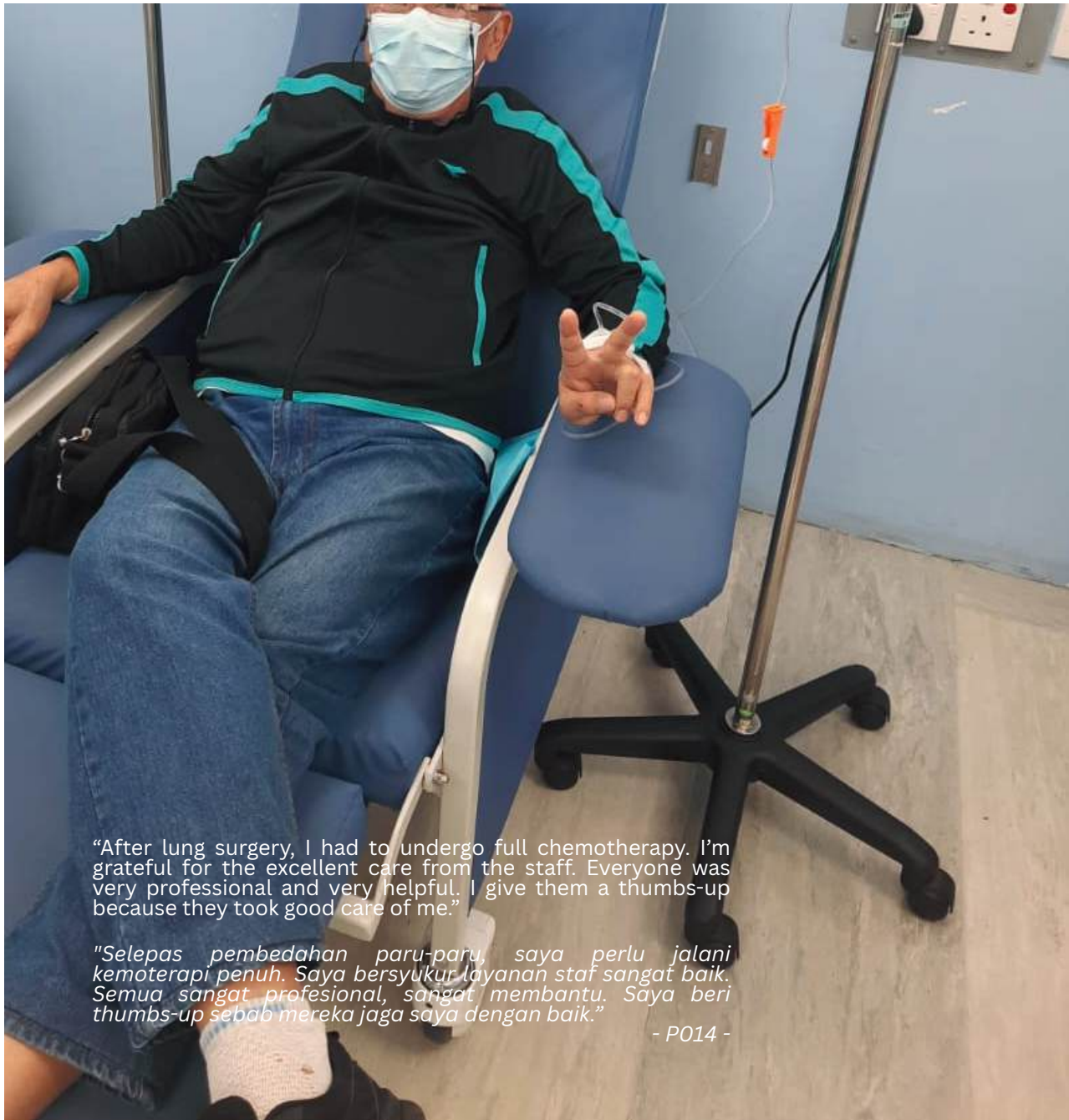
- P009 -



"Every time I see the airport, my heart remembers: when will I be able to go back to my hometown?"

"Setiap kali nampak airport, hati teringat : bila lagi saya nak balik kampung?"

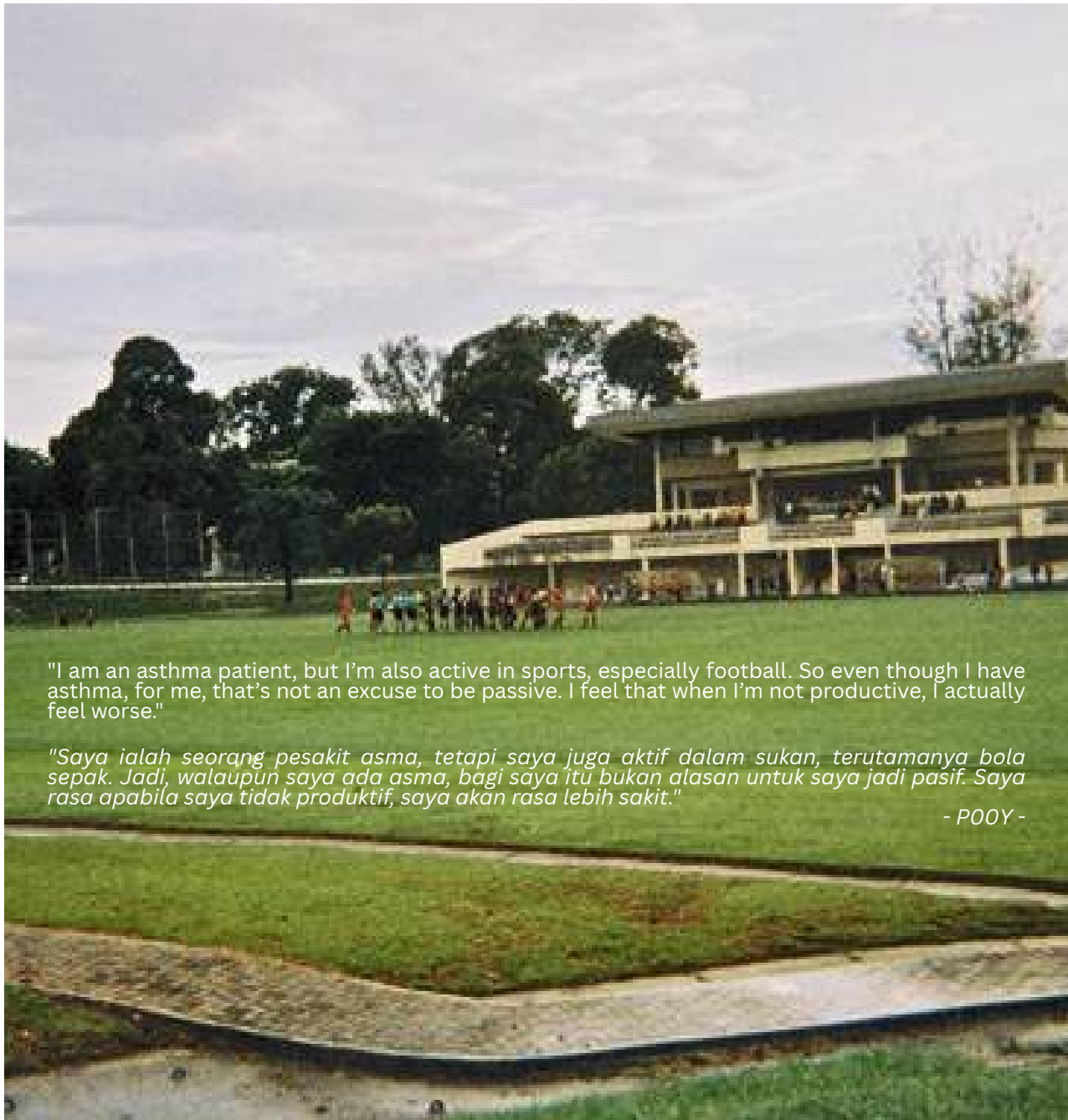
- P009 -



"After lung surgery, I had to undergo full chemotherapy. I'm grateful for the excellent care from the staff. Everyone was very professional and very helpful. I give them a thumbs-up because they took good care of me."

"Selepas pembedahan paru-paru, saya perlu jalani kemoterapi penuh. Saya bersyukur layanan staf sangat baik. Semua sangat profesional, sangat membantu. Saya beri thumbs-up sebab mereka jaga saya dengan baik."


- P014 -



"I am an asthma patient, but I'm also active in sports, especially football. So even though I have asthma, for me, that's not an excuse to be passive. I feel that when I'm not productive, I actually feel worse."

"Saya ialah seorang pesakit asma, tetapi saya juga aktif dalam sukan, terutamanya bola sepak. Jadi, walaupun saya ada asma, bagi saya itu bukan alasan untuk saya jadi pasif. Saya rasa apabila saya tidak produktif, saya akan rasa lebih sakit."

- POOY -

A photograph of a sunset over the ocean. The sky is filled with soft, golden light from the setting sun, which is partially obscured by clouds. The water is dark and calm, reflecting the light from the sky. In the foreground, there are dark, jagged rocks that appear to be part of a coastline or a breakwater. The overall mood is serene and contemplative.

“As a family, we often go swimming in the sea. I want to swim, my husband and child can swim but I can’t because I have asthma. I’m afraid I’ll drown in the water because I know how it feels to struggle to breathe. But I hope I can have the strength like the waves, rising and falling, yet never stopping from crashing onto the shore. I pray that I never give up, no matter how difficult or breathless I feel. I will keep going, for my children.”

“Sebagai sebuah keluarga, kami selalu pergi berenang di laut. Saya nak berenang, suami dan anak saya boleh berenang, tapi saya tak boleh sebab saya ada asma. Saya takut saya lemas dalam air, sebab saya tahu bagaimana rasanya sesak nafas. Tapi saya harap saya boleh ada kekuatan seperti ombak, ada pasang surutnya tapi tak pernah berhenti menghempas pantai. Saya berdoa agar saya tak pernah berputus asa, tak kira betapa susah atau sesak nafasnya saya. Saya akan terus hidup untuk anak-anak saya.”

- POOM -

Words of Acknowledgement

We would like to extend our deepest thanks to every photographer-storyteller who trusted our team with their images and their stories. Your valour and creativity have shaped this project from its first shutter-click to the final caption. We are grateful to the Selangor Health Department and Klang Health District, Family Physicians, medical officers and clinic staffs in Klang who facilitated recruitment and provided safe spaces for dialogue. Special appreciation to the RESPIRE Malaysia teams from Universiti Malaya and Universiti Putra Malaysia.

These pages are only a beginning. If a photograph here moved you, carry its lesson forward: advocate for breathable cities, listen to those who wheeze, and remember that dignity begins with a single, easy breath.

Thank you for journeying with us.

Ucapan Penghargaan

Kami ingin merakamkan setinggi-tinggi penghargaan kepada setiap jurugambar-pencerita yang mempercayai pasukan kami dengan imej dan kata-kata mereka. Keberanian dan kreativiti anda telah membentuk projek ini dari klik butang kamera yang pertama pertama hingga kapsyen terakhir. Kami amat berterima kasih kepada Jabatan Kesihatan Selangor dan Daerah Kesihatan Klang, Pakar Perubatan Keluarga, pegawai perubatan dan kakitangan klinik di Klang yang memudahkan proses pencarian peserta dan menyediakan ruang untuk temubual. Penghargaan khas juga kepada pasukan RESPIRE Malaysia dari Universiti Malaya dan Universiti Putra Malaysia.

Halaman-halaman ini hanyalah permulaan. Jika salah satu gambar di sini menyentuh hati anda, bawalah pengajarannya ke hadapan: sokonglah bandar yang mempunyai udara bersih, dengarlah mereka yang berbunyi ketika bernafas, dan ingatlah bahawa maruah bermula dengan satu nafas yang mudah.

Terima kasih kerana bersama kami dalam perjalanan ini.



UNIVERSITI
MALAYA



This research was funded by NIHR 16/136/109 and NIHR132826 using UK international development funding from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK government.

