

SAFEGUARDING THEIR FUTURE

Caring for a child with special needs is a lifelong journey but a little planning can go a long way.

WHEN MDM FATIMAH BINTE AHMAD FIRST FOUND OUT THAT HER GRANDDAUGHTER Nur Harlina Binte Mahamad Nahar had special needs, she was at a loss of what to do. "My daughter (Nurhalina's mother) and I pondered about how she would go about her daily life after we had passed on — we became so stressed and worried," says Mdm Fatimah, 60, who is one of Nurhalina's caregivers. That was in the early 2000s, when there was still a lack of awareness about special needs among the general public. However, things are getting better, notes Mdm Fatimah. "Today, people understand about special needs more. But life for Nurhalina is still hard."

Nurhalina, who lives in Chua Chu Kang, is 16 this year but has difficulties speaking and expressing herself. "It is through hand signals," explains Mdm Fatimah. "For example, when she does the action of carrying a backpack, we know she wants to go *jalan-jalan* (for a walk)." Despite the communication barrier, Nurhalina gets on well with her brother and sister, aged four and 14 respectively. "The siblings love their *kakak* (elder sister) very

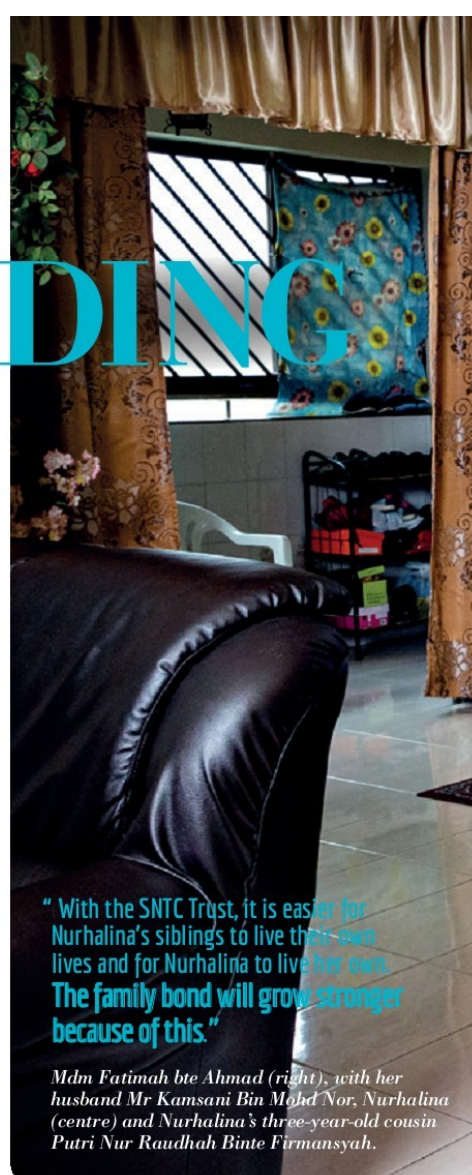
much and enjoy playing with her," says Mdm Fatimah.

However, Mdm Fatimah and Nurhalina's parents plan to let her stay in a Muslim residential home when they are too old to care for her. "We do not want to impose on Nurhalina's siblings, as they will have families and responsibilities of their own," says Mdm Fatimah.

Nurhalina's mother, Mdm Lenny Marlina Binte Kamsani, approached the principal of Movement for the Intellectually Disabled of Singapore (MINDS), the school that Nurhalina attends, to understand how to make plans to cater to her future care needs. The principal pointed them to the Special Needs Trust Company (SNTC).

Established in 2008 with the support of the Ministry of Social and Family Development and National Council of Social Service, SNTC provides affordable trust* services. It also helps families draw up a care plan that details alternative care arrangements and financial requirements for a person with special needs if the primary caregiver is no longer around or able to provide care. "It was just what we needed — support that we could rely on," says Mdm Fatimah. But as she reveals, raising the \$5,000

* A Trust is a legal relationship in which an individual or institution (known as the Trustee) holds assets, subject to a legal obligation to keep or use the assets for the benefit of another (known as the Beneficiary). Source: SNTC



"With the SNTC Trust, it is easier for Nurhalina's siblings to live their own lives and for Nurhalina to live her own. The family bond will grow stronger because of this."

Mdm Fatimah bte Ahmad (right), with her husband Mr Kamsani Bin Mohd Nor, Nurhalina (centre) and Nurhalina's three-year-old cousin Putri Nur Raudhah Binte Firmansyah.

THE SOONER, THE BETTER

Here are some things to consider when charting a care plan for your care recipient:

→ **DO IT EARLY.** Avoid unnecessary stress and confusion by thinking about future care early. Be sure to inform other immediate members of the family of these care plans. This will help them to clearly communicate the care preferences of the person with special needs to doctors and relevant service providers.

→ **USE AVAILABLE TOOLS.** Besides setting up a Trust Fund, draft a Letter of Intent (a document that passes vital information about a person with special needs to future caregivers), or apply for a deputy guardian



早规划，早安心

以下是在您为受护者制定看护计划时需注意的一些事项：

→ **尽早开始。** 尽早开始规划未来的看护计划，以避免不必要的压力和困扰。请务必将这些看护计划告知其他直系亲属。这将有助于他们向医生及相关服务提供者清楚说明有特殊需求人士的看护偏好。

→ **利用现有的资源。** 除了设立信托基金，您还可以起草一份意向书（向未来看护者说明有特殊需求人士重要信息的文件），或申请一位代理监护人。在您去世之后帮助照顾您的孩子。您可以向律师提出这些事宜方面的协助。欲知更多详情，请浏览 www.sntc.org.sg。

to help care for your child with special needs after your death. A lawyer can help with these. For more information, visit www.sntc.org.sg.

→ **ALWAYS ASK YOURSELF THESE:** "What makes his or her day meaningful?" and "What are his or her health condition and goals of care?" Your answers can help you make an appropriate decision.

Source: Agency for Integrated Care



→ 经常问自己以下问题。
“是什么让他或她的生活有意义？”以及“他或她的健康状况和看护目标是什么？”您的答案可帮助您做出正确的决定。



needed to set up the SNTC Trust was challenging.

That was when Nurhalina's family learnt about the Islamic Religious Council of Singapore (MUIS) Support for Persons with Special Needs Scheme, a collaboration between MUIS and SNTC. Aimed at low- and middle-income Muslim families, the scheme sponsors the initial \$5,000 required to set up the trust. MUIS will also channel up to \$5,000 on a one-to-one matching basis to encourage beneficiaries to take ownership of the trust and plan for regular top-ups.

ADDED SECURITY

Thanks to the support from MUIS, Nurhalina's caregivers now enjoy a peace of mind when they think about the future. Assisting Nurhalina's family is Senior Case Manager from SNTC, Ms Koh Mui In. "We meet the family once a year to review the care plans. We also discuss the various types of financial resources that they can use to top up the Trust," Ms Koh tells *BRIDGE*. These include nominating their Central Provident Fund (CPF) monies and insurance policies for future injection into the Trust.

But as Ms Koh stresses, besides looking into financial resources, SNTC Case Managers also educate caregivers on the various care facilities and accommodation options available for the continuity of care of the beneficiaries. It gives the caregivers a peace of mind to learn about their options.

Having regular catch-up sessions with beneficiary's families ensures that these care plans are relevant. These sessions are also a chance for families to highlight any special care plans they would like to adopt. "This is very important for us, as we want to make sure Nurhalina is cared for in a facility that respects her Islamic faith," says Mdm Fatimah.

Mdm Fatimah stresses that the family's decision to set up a trust is not akin to abandoning her granddaughter or her showing little faith in her other grandchildren. "I know they will continue to visit Nurhalina and be a part of her life. But with this trust, I am making it easier for them to live their own lives and for Nurhalina to live her own. The family bond will grow stronger because of this." **B**

→ For more information on setting up a SNTC Trust, visit www.sntc.org.sg.

→ For more information on the MUIS Support for Persons with Special Needs Scheme, www.muis.gov.sg.



Berikut adalah beberapa perkara yang perlu dipertimbangkan apabila merancang pelan penjagaan untuk individu yang akan menerima penjagaan daripada anda:

→ **LAKUKAN AWAL.** Elakkan tekanan dan kekeliruan tentang penjagaan di masa hadapan dengan memikirkannya awal. Pastikan anda memaklumkan ahli-ahli keluarga terdekat yang lain tentang pelan penjagaan ini. Ini akan membantu mereka untuk berkomunikasi dengan pilihan rawatan bagi individu berkeperluan khas kepada doktor dan penyedia perkhidmatan yang berkaitan secara jelas.

→ **GUNAKAN SUMBER-SUMBER YANG ADA.** Selain membuka sebuah Dana Amanah, draf Surat Hasrat (dokumen yang menyampaikan maklumat penting mengenai seseorang yang berkeperluan khas kepada penjaga masa depan), atau memohon untuk mendapatkan seorang timbalan penjaga untuk membantu menjaga anak anda yang berkeperluan khas selepas kematian anda. Seorang peguam boleh membantu menguruskannya. Untuk maklumat lanjut, lawati www.sntc.org.sg.

→ **SELALU TANYAKAN DIRI ANDA PERKARA INI.** “Apakah yang membuat harinya lebih bermakna?” dan “Apakah keadaan kesihatan dan matlamat penjagaannya?” Jawapan anda boleh membantu anda membuat keputusan yang sesuai.



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→ **Meminta bantuan dan sokongan.** Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti.

→ **Kendalikan dengan baik.** Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti.

→ **Ulangi maklumat.** Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti. Dapatkan sokongan daripada ahli-ahli keluarga, rakan-rakan, atau komuniti.