

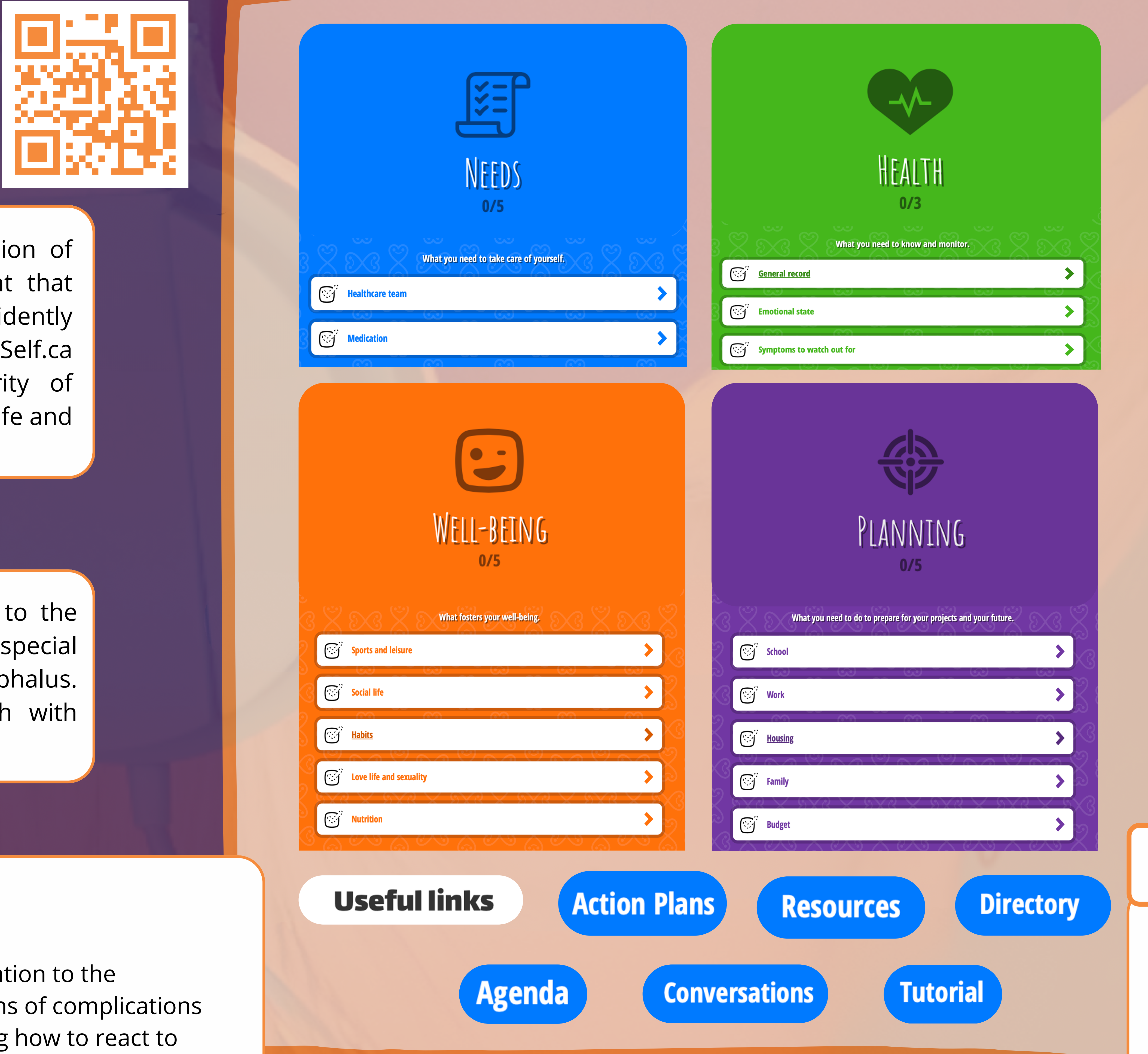


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Pensatout.ca / Notes2Self.ca

Note2self: a virtual assistant to help prepare youth with spina bifida or congenital heart disease for their transition to adulthood



2018

The Spina Bifida and Hydrocephalus Association of Quebec has developed a web-based assistant that helps youth manage their health and confidently navigate their transition to adulthood. Notes2Self.ca or Pensatout.ca (in French). The particularity of Notes2self is to see the transition as a stage of life and not just a step in the care pathway.

Concept

Note2Self is a mobile website that responds to the challenge of the transition of patients with special health care needs such as spina bifida/hydrocephalus. The application was later adapted for youth with congenital heart disease.

Context

The challenges of transition such as :

- finding a new care team, gathering the information and materials needed for care
- establishing routines and good lifestyle habits
- paying attention to the warning signs of complications and knowing how to react to them
- planning appointments, social life and studies issues

These are some of the aspects taken care of by application, a tool that combines check list functions, planning tools and practical resources on a platform that young people love, their mobile device.

7800

Since the launch of the application 7800 francophone and anglophone youth with spina bifida and/or hydrocephalus have used it.

They commented:

« Pensatout est l'outil qu'il nous fallait pour mieux aborder notre transition; Pensatout m'aide à m'organiser ; Je peux utiliser Pensatout selon mes besoins ».

Missions

Notes2Self offers young people the opportunity to complete missions:

- **Understand and meet their basic needs** : care team, medication, outpatient and home health care routine, equipment, transportation
- **Develop healthy lifestyle habits and take care of their well-being**: plan leisure activities, regular sports activities, take an interest in their diet, etc
- **Watch over their health**: do small express tests that allow them to go around everything, both in terms of physical and mental health, and to remain vigilant to possible complications
- **Plan their future**: the tool encourages young people to think about their future plans, higher education, founding of a family, etc
- **Engage in conversations with people**, whether professionals or others, to access a host of resources, and to prepare action plans to better achieve their personal goals
- **Program reminders in their diary** - and the young person occasionally receives emails inviting them to carry out a short self-examination

Conclusion

In conclusion, this ludic application developed for the transition of youth with spina bifida/hydrocephalus and congenital heart disease is a promising tool to help these special populations succeed in all aspects of their life during this important phase. The application can also be modified to suit other chronic conditions

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The adaptation for youth with congenital heart disease was launched in February 2023 and the comments so far are encouraging.

