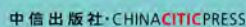


DESIGN MANAGEMENT

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Michael's Finger

迈克尔的手指 没有蛋白质, 人怎么生活?

作者: 保罗·贝内特 (Paul Bennett), IDEO全球首席创意官。

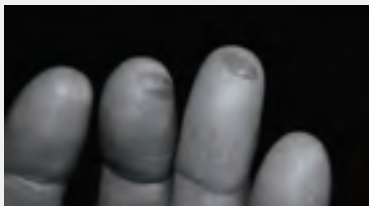


那是2004年4月的一天, 那时我在伦敦, 坐在我面前跟我对话的17岁少年肖恩 (Sean) 来自汉兹沃思一个工薪家庭, 这个地区位于英国米德兰兹郡的伯明翰, 这里的治安出了名的难治理。他说话风格怪异、含混不清, 浓重的口音中, 夹杂着牙买加土话和英式街头俚语。我也有来自伯明翰的亲属, 所以深悉鼻音浓重的当地方言, 但是即便如此, 要想听懂他、跟上他的思路, 也还是颇费周折。

我总感觉肖恩在刻意隐瞒些什么。他有苯丙酮尿症 (PKU), 这是一种严重的代谢紊乱病症, 我们当时受客户委托, 正在做这方面的研究。客户公司生产一种膳食补充剂, 可以缓解病症。众所周知, PKU指的是人体丧失了加工任何复杂形式蛋白质的能力, 也就是说, 病患只能依赖清淡的低蛋白质食品, 不能吃红肉、鸡肉、奶酪、坚果或豆类, 面包、意大利面、米饭等主食的摄取也必须严格控制, 多数食物无法被消化。

PKU病人被迫食用一种粉状的膳食补充剂, 无口感、无味道, 吃起来就像在咀嚼粉笔一样, 非常干涩恶心。在客户公司总部, 我信心满满、故作勇敢, 嘎嘣嘎嘣嚼了几口, 结果刚吃进去, 就无法抑制地吐在了他们昂贵的会议桌上。下面的人面面相觑, 静默不语。

长期服用它会让人深感绝望。对年轻人来说, 头16



(图1) 深受苯丙酮尿症 (PKU) 的折磨, 12 岁的迈克尔指尖遍布着被泡罩包装磨出的水疱。

年一定要严格遵守苛刻的服用疗程, 否则后果严重: 智力迟钝、大脑功能障碍、头小畸形、情绪障碍、运动机能紊乱、产生诸如 ADHD (注意力缺陷/多动障碍) 的问题行为等。我不知道肖恩是否或多或少被这些病症影响着。

聊了 20 分钟大部分有关音乐的话题之后, 他明显放松下来了。我有糖尿病, 所以我跟他说起这个病给我带来的痛苦, 饮食和外出就餐时给我带来的困难——没法像正常人一样。慢慢地, 我赢得了他的信任。

终于, 我问起了他有关 PKU 的事。他跟我说, “真他妈烦人, 这玩意儿。” 我问他为什么。他叹了口气, 开始叙述几年前在学校发生的事情, 当时他只有 12 岁——这个对普通人来说都不那么好过的年纪, 更别提对于他这样一位身患重病的城市少年。肖恩的病总成为同学口中的笑柄, 他们叫他“废柴”, 因为他只能吃母亲为他特别制作的三明治, 用的是硬纸板似的 PKU 面包。他想和其他孩子一样, 冲到汉堡屋里, 对着油腻腻的汉堡和薯片大快朵颐, 咕咚咕咚喝着可乐。但是, 现实中他只能在学校里找一个安静的角落, 把自己藏起来, 默默地吃着午餐。

一天, 一群小混混威逼肖恩吃下一个土耳其烤肉堡——油腻腻的, 鬼知道面包里裹的到底是什么动物的肉。用肖恩的话来说, 他们想看看肖恩吃下去后“他的头



(图2) IDEO 团队为 PKU 患者设计了一款一款午餐盒大小的高浓度挤包式制剂, 外包装色彩跳跃, 仿佛功能或运动饮料。这款产品可以让那些之前对药品不耐受的孩子顺利服药, 也让他们走出被嘲笑的阴影, 拥有彩色的青春。

是不是会爆开”。他们把这东西硬塞到他嗓子眼儿, 然后把他甩到地上, 两眼放光充满期待。但是什么也没发生。原来 PKU 症状是逐渐累积的, 表征需要很长时间。他们等得无聊, 就走开了。这件事对于肖恩的身体来说并无大碍, 但是心理上却备受打击——打那以后, 他无时无刻不生活在恐惧之中, 担心又会有什么怪事发生。他拼命想得到别人的认可, 所以最后加入了他们, 每天去汉堡店, 把 PKU 食品扔在一边。

与此同时, 肖恩的母亲还不知道发生的这一切——作为一个单亲妈妈, 她文化程度低, 工作卖力, 自己的身体也不好——只知道儿子的学业一落千丈, 他的注意力开始分散, 思维速度变慢, 情绪波动更明显。终于她带着儿子去了医院, 医生发现, 肖恩的酶水平已远低于正常水平, 他的智力已经开始衰退。

从跟肖恩这样的年轻人的聊天中, 你会发现无数类似的故事。12 岁的男孩迈克尔给我看了他的双手 (图1)。他的拇指和食指指尖遍布着破开的水疱。我问他是怎么回事, 原来是粉状的食物难吃到难以下咽, 和我一样, 他吃了就忍不住要吐。在这种情况下, 他别无他法, 只能吃药: 每天三次, 每次 40 片, 共 120 片。也就是说每周服用的药超过 800 片。

这些药丸都是泡罩包装, 所以每周三次, 他和他>>

母亲都会坐在厨房饭桌前，将这些药片全部挤到一个大碗里，然后再装到小袋子里带到学校。和肖恩一样，迈克尔的同学也嘲笑过他吃药的行为，说他是“毒贩子”，所以他也只好躲起来，到别人看不见的地方去。我最初看到他的时候，觉得他和他妈妈不像母子，倒像是朋友，这是一种奇怪而深厚的友谊。我感觉母子俩就像是共同作战的队友，共同捍卫着他的防线。

那天结束后，我坐在PKU小组中，问他们对这样一款能够帮助他们的产品，希望是什么样子的，摸上去有什么感觉。“普普通通，和正常的一样。”一个男孩说道。另一个说：“酷一点儿，就像是耐克的产品。”

IDEO团队在桌上摆放了一些包装食品：健康食品、有异国特色的日本产品、药物补充剂、美国的运动特制蛋白产品，还有一些临时加上去的，从英国超市里买来的我们都习以为常的东西，类似糖果、碳酸饮料、麦当劳套餐、薯片。孩子们立刻被后一类产品吸引。没有人想要特立独行——受疾病拖累直到脑子爆开，或被称为“毒贩子”——他们不希望自己和其他孩子有任何差异。

那天晚上，我记得在笔记本上写下这几个字：“不要（刻意）设计。正常（就好）。”

终于，我们共同开发出了一款十分简单的产品。6个月之后，经过多次设计、提炼、反复完善、配合建模和多轮研究，它终于上市了：一款午餐盒大小的高浓度挤包式制剂，各种口味都是他们帮忙挑选出的，外包装的色彩非常跳跃：有霓虹绿、粉色、橙色。看上去很酷，仿佛功能或运动饮料，含有一个小吸嘴，你可以快速将其吸入嗓子，不会再有硫黄味带来的反射般的呕吐反应。

这款产品可以让那些之前对药品不耐受的孩子顺利服药，还赢得了设计大奖。销量大增，市场份额提升。后来客户将公司卖给一家企业集团，CEO（首席执行官）还在离任演讲中将其称为公司历史上的巨大成功。

这一切当然都很棒，但是这并不是我们的初衷。迈克尔手指尖上的水疱，还有他告诉我他特别想学吉他，这才是这个项目的初始动力。说不定现在他真的可以弹吉他

了。虽然在那之后我再没有和肖恩聊过，但是我想，他会去母亲一直盼望他去的技术学校，那里没有帮派青年，他会在那里走出自己的人生，让母亲为他感到骄傲。●

Michael's Fingers

How people live without protein



• Paul Bennett in Thoughtful Design

I am sitting talking to Sean, a 17-year-old working-class kid from Handsworth, a notoriously tough area of Birmingham in the UK's Midlands. His speech is strangely inarticulate and slurred, his accent heavy and laced with slang—original Jamaican patois mixed with English street. I have family from Birmingham and know the nasal dialect, but even I am struggling to understand and keep up.

What I do understand is that Sean is hiding something. He has a condition known as Phenylketonuria, a serious metabolic disorder that we are studying for a client of ours. They manufacture a food supplement, which helps moderate the effects. PKU, as it is known, is an inability for the human body to process any form of complex protein, meaning that the sufferer is resigned to a life of bland, low-protein food: no red meat, chicken, cheese, nuts, or legumes. Staples such as bread, pasta and rice have to be carefully monitored. Most are simply impossible to digest.

The product that those with PKU are forced to consume is a powdered food supplement, devoid of any texture and flavor. It is chalky and vile—like a sulphurous barium. Buoyed with confidence and false bravado, I chugged it down in our clients' headquarters and immediately vomited it all over their expensive conference table. A stone silence followed.

Living with this is a bleak existence, and for the first 16 years of life, adherence to a strict regimen is critical or things go horribly awry: severe mental retardation, brain-function abnormalities, microcephaly, mood disorders, irregular motor functioning, and behavioral problems such as ADHD can set in. I wonder if Sean is trapped somewhere on this spectrum.

After twenty minutes of talking, about music mainly, he visibly relaxes. I am diabetic, so I tell him how that sucks for me and how hard it is to deal with food and eating out—being normal. I am slowly gaining his trust.

I finally ask him about his PKU. He tells me it is “a big fucking stress, this thing.” I ask why. He sighs and tells me a story about being at school a few years previous, when he was 12 or so—tough years for anybody, never mind an inner-city youth with a life-threatening condition. Sean’s disorder seemed to endlessly amuse his classmates, who called him a ‘fag’ for having to eat specially prepared sandwiches of cardboard PKU bread that his mother had made for him. He wanted to be cool like the other kids and bunk-off to the local burger joint to eat greasy food and chips, and drink Coke. Instead, he ate his lunch quietly, in a corner of the schoolyard, trying to be invisible.

One day a group of local lads had decided to see what would happen if they held Sean down and forced him to eat a kebab—a mound of fat, meat from some God-knows-what-animal, and grease wrapped in bread. They wanted to see, Sean said, “if his head would explode.” They shoved the food down his throat and then pinned him to the ground, watching expectantly. Nothing happened. Turns out PKU is cumulative and takes a long time to show. Bored, they slumped off. Sean wasn’t physically scarred by the event, but mentally he was devastated—in constant fear of seeming different or weird from then on. He desperately needed their approval, so from then on he joined them every day at the burger joint, throwing away his PKU food.

Having no idea that this was happening, his mother—a single parent, uneducated, hard-working, and ill-equipped to begin with—watched her son’s grades diminish, his attention increasingly waver, his mental processing speed slow, and his mood swings worsen. Eventually she took him to the doctors, who found that Sean’s enzyme levels were way off and that retardation had already started to set in.

Talking to teenagers such as Sean unveiled story after story like this. One boy of about 12, Michael, showed me his hands. He had raw, open blisters on the tips of both his thumbs and forefingers. I asked him what they were. It turned out that he could not ingest the powdered food formula because it tasted so bad, and like me, made him throw up. That being the case, he had no choice but to take pills: 40 of them, three times a day, totalling 120 pills. That’s over 800 pills a week.

The pills came blister-packed, so three times a week, he and his mother sat at their kitchen table and popped hundreds and hundreds of small tablets into a large bowl and then decanted them into small baggies to take to school. As with Sean, Michael’s peers had accused him of taking drugs, of being “a pusher,” so he had withdrawn and gone underground. When I first spotted him, my immediate thought was that he and his mother seemed more like peers than parent and child, strangely best-friendly. I realized listening to them that they were joined together, battling at the front lines on his behalf.

Sitting around with the PKU group at the end of that day, I asked them how they would like the products that helped them with this condition to look and feel. “Normal, nothing special,” said one boy. “Cool, like something from Nike,” said another.

The IDEO team had collected a bunch of packaged food on the table: health foods, exotic stuff from Japan, medical supplements, special sports protein products from the US, and as

an afterthought, some “regular” stuff from supermarkets in the UK like candy, fizzy drinks, McDonalds meals, and potato chips. The kids immediately gravitated to the latter stuff. Not wanting to be singled out—held down until their heads exploded, or called “pushers”—not wanting to be anything other than kids.

I remember writing in my notebook that evening: “Not ‘designed.’ Normal.”

Together we came up with a very simple product. Six months later, after many designs, refinements, iterations, prototypes, and rounds of research, it hit the market: a small, school-lunch-box-sized squeeze-bag of highly concentrated product, with intense flavors that they helped us select, and pop-colored packaging in neon green, pink, and orange. It looked cool, like an energy or sports drink, with a small nozzle so you could shoot the product down your throat, avoiding the gag-reflex that the sulphurous smell brought.

It allowed kids who couldn’t previously tolerate the product to finally take it. It won a design award. It drove sales and market share. And when the client we designed it for eventually sold the company to a large conglomerate, the CEO’s called it out as a success story in his parting speech.

All of that was great, of course, but it wasn’t why we did what we did. It was the blisters on the ends of Michael’s fingers, and him telling me that he really wished he could learn guitar, that drove this project. Maybe now he will be able to play. And though I haven’t spoken to Sean since, I think about him finding his way through technical college, where there are no more thugs, where his mother prayed he would go, and making her proud.